DOCUMENT RESUME

ED 352 746 EC 301 293

AUTHOR O'Brien, John, Ed.; O'Brien, Connie Lyle, Ed.
TITLE Remembering the Soul of Our Work. Stories by the Staff of Options in Community Living.
INSTITUTION Minnesota Univ., Minneapolis. Inst. on Community Integration.; Options in Community Living, Madison, WI.; Responsive Systems Associates, Lithonia, GA.; Syracuse Univ., NY. Center on Human Policy.
SPONS AGENCY National Inst. on Disability and Rehabilitation Research (ED/OSERS), Washington, DC.
PUB DATE 92
CONTRACT H133B80048
NOTE 163p.
AVAILABLE FROM Options in Community Living, 22 North Second St., Madison, WI 53704.
PUB TYPE Collected Works - General (020) -- Creative Works (Literature,Drama,Fine Arts) (030)

EDRS PRICE MF01/PC07 Plus Postage.
DESCRIPTORS Attitudes; *Disabilities; *Independent Living; *Mental Retardation; Normalization (Handicapped); *Personal Narratives; *Quality of Life; Quality of Working Life; Staff Development; Values

ABSTRACT

The personal stories in this collection are by the staff of an agency which provides "supported living" services to adults with mental retardation and other disabilities. The stories were written to be read at monthly staff meetings when time is set aside to clarify and renew the organization's values. Introductory material offers suggestions for other agencies wishing to use this approach, provides basic information on the Options in Community Living organization, and describes three typical clients. The brief narratives are grouped into the following categories: ordinary moments, everyday triumphs, assistance, understanding, how people change, dreams, family, friends, money matters, fighting the system, clienthood, control, suffering and death, teachers, words of power, "why I do this work," and writing stories at work. (DB)

****
* Reproductions supplied by EDRS are the best that can be made *
* from the original document. *
****

ED352746

REMEMBERING
THE SOUL OF OUR WORK

STORIES BY THE STAFF OF

OPTIONS IN COMMUNITY LIVING

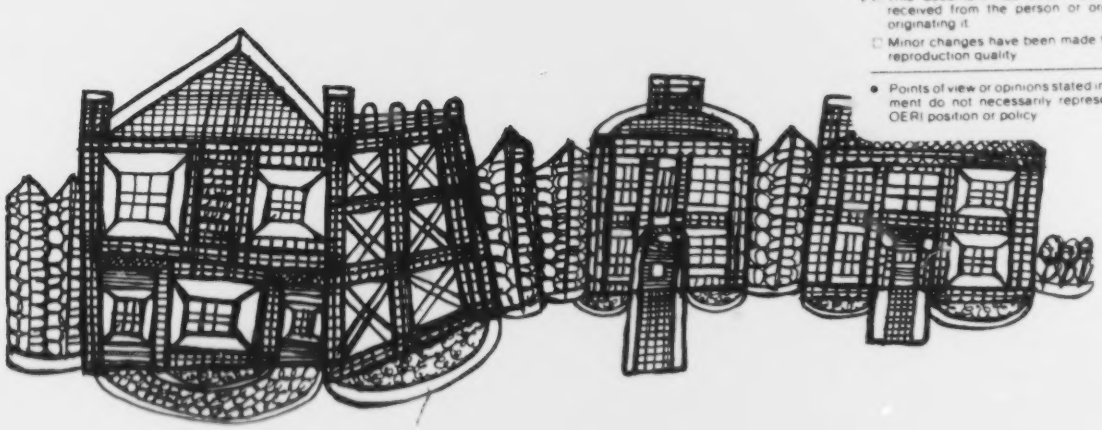
MADISON, WISCONSIN

U.S. DEPARTMENT OF EDUCATION
Office of Educational Research and Improvement
EDUCATIONAL RESOURCES INFORMATION CENTER (ERIC)

☑ This document has been reproduced as received from the person or organization originating it.

☐ Minor changes have been made to improve reproduction quality.

• Points of view or opinions stated in this document do not necessarily represent official OERI position or policy



EC 301293

EDITED BY JOHN O'BRIEN AND CONNIE LYLE O'BRIEN

BEST COPY AVAILABLE

Remembering the Soul of Our Work

Stories by the Staff of Options in Community Living

Madison, Wisconsin

Edited by
John O'Brien & Connie Lyle O'Brien

Forward by
Steve Taylor

Cover art by Carter Todd
Cover design by Eric Johnson

Additional copies of this book are available from:

Options in Community Living
22 North Second St.
Madison, WI 53704
(608) 249-1585

©1992 by Options in Community Living. All rights reserved.

The editing of this book was partially supported through a subcontract to Responsive Systems Associates from The Center on Human Policy, Syracuse University for the Research & Training Center on Community Living. The Research & Training Center on Community Living is supported through a cooperative agreement (Number H133B80048) between the National Institute on Disability & Rehabilitation Research (NIDRR) and the University of Minnesota Institute on Community Integration. Members of the Center are encouraged to express their opinions; these do not necessarily represent the official position of NIDRR.

This is a book of stories composed by staff members of Options in Community Living between 1987 and 1991. These people wrote and read their stories to one another during regularly scheduled staff meetings as a contribution to personal and organizational renewal.

Ellen Backus
Peter Bazur-Leidy
Timothy Boylan
Theresa Fishler
Missy Fizzell
Kathy Hart
Cindy Herschleb
Sharron Hubbard
Gail Jacob
Kathy Lemke
Carol Lofgren
Amy Lutzke
Kathryn Mazack
Polly Molenaar
Janet Morgan
Gretchen Mullins
Sid Nichols
Julie Nichols-Younes
Maureen Quinlan
Sarah Salzwedel
Gwen Schmidt
Alice Sosinsky
Diane Steele
Kim Turner
Leslie Wilmot

As the number of stories grew, Options staff began to share some of them with others concerned about building community with people with disabilities. They discovered that their stories effectively communicate some of the qualities of thought and action that make their work distinctive and meaningful.

Contents

Foreword	vii
Reading This Book	1
About Options in Community Living	3
Sticking With People: A Context for the Stories	4
Chris	4
Jean	6
Jim	8
Ordinary Moments	11
I guess we're equal now.	11
Shopping with David	12
Wanda's Lunch	13
I haven't played since one of your last visits	14
Gumption, Humor, Adversity, Tenacity, Love, and Other Assorted Ingredients	15
Crashing Dean's Retirement Party	15
I hope everybody likes spaghetti	16
Off to the Races	17
Thanksgiving Eve	18
Christmas with Alice	19
Nice Holiday	19
On Being a Support Worker in Time of War	20
Celebrating Martin Luther King's Birth in Time of War	21
Everyday Triumphs	23
Class Ring	23
Red Duke's Dearest Fan Is on Cloud Nine	23
The Birthday Card	23
Housewarming	24
It Was Sue's Day	25
Don't Give Up the Ship	26
First Vacation	27
Assistance	29
Options	29
The Magic of Communication	29
Moving	30
New Apartment?	31
Weekends with Bev	32
Recruitment Pursuit	33
Waiting Around	34

A Day at the Brewers 34

Understanding 37

Getting Out 37
The Places 37
The Best Dressed Dishwasher 39
I Finally Got Around to Meeting Jean 39
Oxymoron 40
Babies 40
My Name Is Dan 42

How People Change 45

From Badger Camp to Milwaukee to (?) 45
Alex Changed His Shirt 46
This Year, Nancy Was Glowing 46
Speak Up, Man 47
I Think I Finally Made It 48
The Art of Freedom 49
Giving People the Space To Be Who They Are 50
I Wonder If She Wonders 51

Dreams 53

The Best Strawberry I Ever Ate 53
August,1993 53
Dreams 54
A Story in Two Parts 55
Roberta 56
Some Unanswered Questions 57
Pat's Goal 57
The Beaches of Waikiki 58

Family 61

One of the Best Visits 61
Other People 62
Family 62
Blue, White and Awful Pretty 64
Home for Christmas 64
A New Beginning 66
Jim's Christmas 67
Twists of Fate 68

Friends 71

Time and Love and Work 71
Wind, Bees and Flying Potato Salad 72

Jim Is Learning To Talk Better 72
Susan's Community 73
Dear Marie, 74
Happy Birthday 75
Joe's People 75
Thoughts on Community Building 78
Romeo's Here 79
I Want... 80
Julie's and Wayne's Dream 80

Money Matters 83
Poverty 83
Disposable Income 84
Don't Use the Candle 85

Fighting the System 87
The ABC's of Clienthood 87
Take a Ride on the Wild Side 88
Neat Little Boxes 88
I Mark the Line 90
On Our System and ANGER 90
A Better Survey 91
No Room at the Inn 92
Mr. Fragile-X 92
Dear Gary, 93
Art & Its Use in Creating a Warm, Home Like Atmosphere 94

Clienthood 95
Pushmi-Pullyu 95
I. Support, II. Privacy 96
Hoops, Hoops, and More Hoops 96
Keith's Privacy 97
Bowling with Eileen 98
He Calls Me His Accountant 99
I'll ask my friend 100
Making Fun 101

Control 103
Contents Glass: Handle with Care 103
In Our Image 104
New Boots 105
Risk 106
James' Wisdom 107

Us and Them 108
Alice Takes the Needle 109
Making Things Perfect 110
California Dreamin' or I'm Getting My Act Together and Taking It on the Road... 111
Armistice 112
Doing the Right Thing 113
Out of Control 113

Suffering & Death 115
Hell on Earth 115
Just Say No 115
Visiting Wanda's Mother's Grave 117
Coming at This Through the Back Door 118
Memorial Letter to Eileen 119
Looking at Life Through the Eyes of Death 120
Memories of Alice 122
I Will Miss... 123
I've Never Heard So Many Nice Things Said About Alice 124

Teachers 127
The Bottom Line 127
"Ruttie, Tuttie, Fresh and Fruitie" 127
A Lady with Guts and Sensitivity 128
With Intense Eyes 129
The Power of One 130
Learning Experiences at Options 131

On Words of Power 133
Liberation 133
Reality 134
Open 134
Surround 135
kon - 'trib - yut 136
Revolution 137
Choice 138
Faded Photographs 139

On Why I Do This Work 141
Aren't You Ever In Danger 141
More Than Words 142
Growing Up at Options 143
The People Here Fill Me Up 144

Options Treats Its Employees the Same Way as the People It Serves 144
Tedious, Messy, & Mundane Things That Really Make a Difference 145
The Most Fast-Paced, Deadline Oriented Job 146
I Know, Because I Have Been There 146
People's Lives Are Chaotic & Mysterious 147

On Writing Stories at Work 149
Writing Stories 149
Memories Fade... 149
A Little Bit of Myself 150
What Writing Stories Does for Me 150
SWS 151
Writer's Block 152
What Happens When You Don't Write Stories 152
Reflections on Story Writing at Options 153
Stories Build Community 154
Stories from Beyond 154
No Room for Imperfection 155

Index 157

Foreword

I am pleased and honored to be invited to write a Foreword to this compilation of stories by the staff of Options in Community Living. Like John O'Brien and Connie Lyle O'Brien, who do a masterful job of editing and organizing these stories, I have long been an admirer of Options and have sought to learn from its successes and its struggles. This collection provides yet another opportunity to learn about the important work of supporting people with disabilities to live with dignity in the community.

Options in Community Living can best be classified as a "supported living" agency and, in fact, has pioneered in the development of this so-called model or approach. But this collection is not about a program model or set of practices and technologies. What is to be learned from this collection has to do with the human side of supporting people in the community: the joys and the frustrations, the victories and the dilemmas.

Running throughout these stories are some powerful lessons for all those involved in or concerned about services for people with disabilities. One has to do with the nature of human services work. Human services work is sometimes fun, sometimes painful, sometimes tedious, and very often difficult. Kathy Lemke writes, "This stuff is hard." Julie Nichols-Younes describes her work as "Tedious, messy, & mundane things that really make a difference."

Another lesson relates to the importance of helping staff to find meaning in their work. Too often human services work is equated with program slots, units of service, and compliance with impersonal rules and policies. The soul is missing and the people are forgotten. As the story-telling in this collection attests, Options encourages all staff to take the time to stand back from the day-to-day grind to reflect on the meaning of their work for both themselves and the people they serve. "The people here fill me up," explains Diane Steele, and this is what human services work should be about.

Perhaps the most important lesson to be drawn from this collection relates to the importance of "sticking with people" or making a long-term commitment to them. As Gail Jacob explains, "Chris will always be in my life." More than anything else, this is what makes Options stand out from most human service agencies. Those who seek to replicate the "Options' model" should be advised to try to emulate its spirit.

Since this is a collection of stories, I cannot resist the temptation to tell one of my own about Options. In 1987, Betsy Edinger and I participated in an evaluation of Options. As part of this evaluation, we visited a number of the people served by the agency. We enjoyed each of these visits, but one will always stand out in my mind. This was our visit to Alice's apartment.

After finally finding Alice's apartment, we knocked on the door and a voice called out from the other side, "I'm not going to let you in!" We explained who we were and told her that we had been informed that she would be expecting us. Alice persisted, "I'm not going to let you in!" For the next five to ten minutes, we stood outside of her apartment trying to talk her into seeing us. Just as we were about to give up, the door opened and Alice invited us into her apartment. As soon as we got inside, she slammed the door shut and announced, "I'm not going to let you out!" Thus began a memorable and enjoyable visit with Alice.

Reading stories by Kathy Lemke, Carol Lofgren, Sarah Salzwadel, and Sid Nichols in this collection, I was very saddened to learn of Alice's death. Their stories capture the character I remember so vividly during my brief encounter. "Alice, I hope in your new life there are cigarettes, peaceful places to sit and rest, a community to belong to and unlimited cups of free coffee," writes Sarah Salzwadel. To be respected as a person and accepted for who and what you are—this is far too uncommon for people on the receiving end of services. Alice and Options were lucky to have found each other.

This collection of stories is being published on the tenth anniversary of Options. We should all join in this celebration. So here's to Options and to Gail Jacob and the other story-tellers there!

— Steve Taylor

Center on Human Policy

Syracuse University

Reading This Book

This book collects about half of the stories shared among the staff of Options in Community Living between 1987 and 1991. These stories were written to be read at monthly staff meetings, when the agency sets aside a regular time to clarify and renew Option's values.

Options staff have found story writing a helpful way to find meaning in their daily work, make sense of difficult situations, raise hard questions, and strengthen their relationships with one another and the culture of their organization. Their stories communicate the challenges, frustrations, dilemmas, and rewards of accepting an organizational and personal commitment to help people with disabilities make and keep their rightful place in community life.

Anyone who wants a better understanding of the experience of assisting people with severe disabilities will find much to think about in these stories. But at least two characteristics of these stories could pose a barrier to learning from them.

- The stories provide brief glimpses of ongoing relationships and careers. They don't offer the history of a situation and the reader seldom finds out what happened next.
- The writers use the stories to explo e what they think about issues of importance to them. These are not position papers or comprehensive essays, they are more like journal entries or personal letters. As Julie Nichols-Younes writes, "If this seems somewhat disjointed or confusing it is because what I am trying to say is not totally clear to me yet."

These characteristics are also strengths because they offer a chance to see what kind of daily experiences seem significant to people who offer community support and how they think about their work and the people they support. But the lessons available here will elude a reader who decides to judge or second guess the storytellers. It will be more fruitful to let these stories communicate the tellers' ideas and insights and frame important questions than to depend on them for answers.

This book organizes the stories around 18 themes that emerged for the editors as we read and re-read them; however, they can be read in any order. While reading the whole book gives a kind of a survey of issues and ideas in supported living, some people may prefer to read one or two stories at once and then take time to reflect.

Write Your Own Stories

The best response to these stories would be to write and tell your own. Here is one way to do so, based on the experience of Option's staff. (There are more ideas in the section called "On Writing Stories at Work," pp. 135-141)

- Invite a group of people to join you. At Options, this activity is for all staff and is part of their work time, but you can form a group in any way that allows you to share your writing with colleagues.
- Commit yourselves to a schedule so that each time the group meets some of the members know that they must read something. Allow enough time so that every member of the group has the chance to read at least three or four stories before you evaluate whether or not to continue.

- Make the group time a time for people to listen carefully and appreciatively to one another. Don't get this mixed up with a consultation or case conference. Group members don't have to come up with advice or solutions. They just need to listen and share their own stories.
- Practice anchoring your writing in the concrete experiences of your work. Look for ways in which work issues resonate with concerns in your personal history. Let yourself write about things that challenge or confuse you. Testing uncertainties about your values that matter to you will usually clarify and strengthen them. Let yourself write about mistakes or misjudgments. Let yourself write about things that evoke strong feelings in you. Notice things that you don't dare write about and then write about them. You can always decide not to read what you have written.
- Remember that this kind of writing is a discipline. Lots of people have had their natural ability to express themselves scared out of them in school. Don't let this be about following rules of grammar or composition. Let it be about finding a voice and a style that suits you and what you want to say. The discipline is to reflect honestly, in writing and then in reading, on what matters to you in your work. Some people who find writing frightening have found this book helpful: Natalie Goldberg (1986). ***Writing down the bones: Freeing the writer within.*** Boston: Shambhala.
- Stories may be amusing or angry or thoughtful or however the experience comes to you. Stories can be entertaining, but you don't have to work to entertain your listeners. The work is in clearly describing some incident or thought that catches your attention.
- Practice and reflection are important. Some people notice that new learning starts to come only after they have used up their initial stock of ideas and spent some time in a dry spell.
- Get started. Write a story now and use it as the basis for your invitation to some of your colleagues.

Write to us

We would be very glad to hear about your reactions to these stories and about your own experiences with writing and sharing stories with your colleagues. Write to:

Gail Jacob
Options in Community Living
22 North Second St.
Madison, WI 53704

A Note on Confidentiality

True to Options' tradition, the people Options serves made their own decisions about how they wanted to be identified in this book. After listening to their story, the person –or someone close if the person is unable to choose– decided whether they wanted the story in the book and whether they wanted to use a pseudonym. Most people chose to use their own first name, a few people chose pseudonyms, and some people chose another name because they liked it better than their own name in that story. In the text, we have not distinguished people who use pseudonyms from people who use their real first names.

About Options in Community Living

In October, 1991 a large, diverse, and noisy group of people gathered in a resturant across the street from Wisconsin's state capitol to celebrate the tenth anniversary of Options in Community Living with music, dancing, baloons, and a few speeches. Gail Jacob, one of the founders and Option's director, identified these accomplishments.

- In ten years Options has provided support to 174 people. We now have 66 staff who support 104 people. {Twenty staff are agency based and the other 46 staff work to support individuals in their homes.] Sixty per cent of the people served by Options moved from institutions, nursing homes or intermediate care facilities into their own homes in community with our help.

- We have never once, in Options' entire history, sent anyone back to live in an institution or facility after they moved to the community.

- When Options started, services were available only to people who did not need live in support. In 1982, we said that all people regardless of disability should be able to live in their own homes. We received state funding that year to arrange support for people who needed attendant care or paid roommates in order to live in their own homes. Now about one half of the people Options supports have some type of in home assistance.

- In 1984, Options helped 10 people relocate to their own homes when Allen Hall [a local facility for people with psychiatric disabilities] closed. A few years later, through the community integration program, Options brought more people home from state institutions for people with developmental disabilities. In 1988, we became part of another effort to move people with developmental disabilities out of nursing homes.

- This year, Options has helped 7 people to move from Orchard Hill [a local intermediate care facility for people with mental retardation]. We are proud of the positive relationships we are developing with these people and their families.

- At the same time, Options continued a strong commitment to adults living with their families who wanted to move to their own places. About 35 per cent of people we support come from their family homes.

Options applies its values in its organization as well. Direct service staff, family members and people who receive services are active participants on our Board and committees and planning processes. Some of our organizational accomplishments include:

- Doubling in–home workers wages in the past three years.

- Reorganizing in 1988 to eliminate paraprofessional positions and thus upgrade half of the agency staff to community support worker positions.

- Supporting three Options staff to start Neighborhood Connections, a brand new agency which can grow to offer many more people the help they need to live in Dane County's communities.

Sticking With People: A Context for the Stories

Most of the stories here recount and reflect on moments in continuing relationships. These three stories, prepared especially for this book, provide a context for the others by offering a view of Options involvement with people over time.

Chris

When Chris was referred to Options for support services in the summer of 1987 her reputation had preceded her. By age 31 she had already been in almost every institution in Wisconsin in addition to several in Michigan, Kansas, Iowa and Minnesota. She had recently moved from a state institution where a sixty day placement somehow stretched into eight years. The Medicaid people had finally deemed her inappropriately placed and ordered her out. There was disagreement about whether her label was mental illness or developmental disability. The records say that she had "mild mental retardation associated with psychiatric impairment with explosive personality, unspecified neurosis, aggressiveness and personality disorder".

In the eight months since leaving the institution and moving to Dane County she had set fire to a group home, assaulted her psychotherapist, assaulted her sheltered workshop supervisor, been kicked out of an intermediate care facility, spent a month in a nearby state institution, spent time in jail and was currently temporarily placed at a county facility. The estimates for serving her in a community setting ran into the hundreds of thousands of dollars a year.

We met Chris for the first time in the day room of the county facility. There were five of us including two friends and advocates for Chris, a county staff and two of us from Options. She had just been released from seclusion for some altercation with staff but she was prepared for the meeting. She told us she really wanted to move to an apartment "as long as there was enough support". Then she gave us a letter she had written for this meeting that listed the areas in which she needed help and described to us what she considered unhelpful. She had written her own service plan! We were amazed by her honesty, her humor and her passion and also by the clarity of her perceptions. Leaving that meeting we knew we were in it for the long haul with Chris.

At the beginning of October Chris moved to a one bedroom apartment and we hired a full time "paid neighbor" who lived nearby and who would provide day to day companionship and support in addition to assistance in daily routines and help in getting involved with community life. A second worker was available on weekends and a case manager also provided support and coordination. It was clear Chris would need to be in control of her life with support available when she needed it. She also had a probation officer (for previous offences) and a psychiatrist who provided medication for Chris to take at her own discretion when she felt out of control. Within a few months Chris was involved with a church and had befriended the parish priest and a woman who worked at the church. She volunteered to help with church dinners and had joined the Altar Society. She found a job at the neighborhood cafe and renewed contact with a wide circle of friends who were former service providers at the various places she had lived in the past.

As we got to know Chris we continued to be in awe of her ability for insight and candor. One minute she would have us rolling with laughter and the next, weeping at the painful stories of her past life: isolation rooms and four point restraints, sexual abuse and physical injury. Yet, she showed us her hunger to learn and to succeed. She kept us honest and let us know when we overstepped our bounds. She blew us away with her wisdom and knowledge of basic truths which was strangely paired with an innocence and naivety from long years of institutional life. It was hard to reconcile the Chris we were getting to know with the Chris on paper. We were also full of self congratulation at our "success" with Chris after so many others in the system had failed her over the years.

About six months after her move the other side of Chris began to emerge. She was fired from her job for threatening a co-worker. Then she had to leave her apartment after neighbors revealed she had been writing them threatening letters for several months. She also went to jail for violating

probation. It was humbling for me to realize what I should have known all along: you can't heal wounds overnight that have been created by years of oppression and abuse. It takes time to learn to trust oneself and others after years of failure and betrayal. Chris landed in jail five more times in the next three years—usually probation holds for threatening a neighbor or doing minor damage to property. A couple of times she landed in the hospital for overdosing on medication. She moved six times in less than four years. She's had four different jobs.

Despite the difficulties, Chris has been tremendously successful in the community, given the story of her life. It has been over a year since Chris has been to jail. She has been off of probation for a year and a half. During the entire time I've known her she's never injured another person. And what is most incredible to me is that Chris has learned something from every crisis. It took a long time for her to believe that she deserved to be in community, that she wasn't bad, that we wouldn't send her back to an institution, that we would stick with her through the rough times. She couldn't quite believe that we would actually listen to her and even admit and apologize when *we* made mistakes. All Chris knew was the system and it's predictable responses. In the past, if she was unhappy all she had to do was cause trouble and she would be sent some place else. It's taken awhile for Chris to learn to value her freedom, her friendships and her life in Madison. Community was an alien world with unfamiliar rules and confusing boundaries.

Chris is also learning that when she is troubled she no longer has to create a crisis to get the support she needs. The system has taught her that when you do well, people whom you rely on move away and if you're in trouble they come around again. We have had to learn to be consistent in our support in good times and bad and to listen carefully to what she is telling us. She continues to challenge us to be more honest, to respect her privacy, and to check our "power over". Many times she has shown more insight than those of us who are paid to use ours in her behalf.

Knowing Chris has been like watching the blossoms of a flower open in slow motion. Actually it's not only watching, but feeling the texture of its petals and smelling its scent. You feel her pain, her anger and confusion. You feel the exhilaration of her accomplishment and the fun of her playfulness. Whether it's crashing in my spare bedroom after an argument with a neighbor or a call to report on a hot date, it's clear Chris has no intention of going this road alone. Chris takes you with her on every step of the journey.

As Chris' confidence in herself increases, her gifts continue to emerge. She is a good friend to others and is always willing to help out. She is a source of support and comfort when friends are having a bad time. She is talented in needlework and is always making gifts for for birthdays and holidays. She is eloquent in telling her story and in advocating to close institutions. She regularly speaks at public hearings and writes letters to policy makers in behalf of people still in institutions. In the past two years she has presented talks at conferences in Vermont, Pennsylvania, Washington and throughout Wisconsin. Chris continues to make new friends. In addition to the many people she's known from the service system over the years there are neighbors that have stayed connected and people from her church. Bad days no longer necessarily turn into crises. Sometimes the anger still seems to boil up out of nowhere, but Chris now has a repertoire of strategies that usually work to handle it: Going for a walk or bike ride and calling at least a dozen people to talk through her frustrations. If that doesn't work she can get away for overnights with her choice of four or five friends who have offered to have her stay or when things are really out of control she can take a pill in her medicine cabinet to calm down. When Chris first moved to an apartment we provided sixty hours of direct support to her over seven days a week. Now Chris gets about 25 to 30 hours of support each week.

Who can predict what's in store for Chris' future? There will be tough times, no doubt. I think there will be a time when she won't need the service system any more at all. I expect she'll get happier and stronger with each year. Chris will always be in my life. I'm pretty sure of that. Nobody has made me work harder than Chris. Nobody can make me laugh harder than Chris.

August, 1991

–Gail Jacob

Jean

Jean is a gentle woman who is 63 years old. She has cerebral palsy and uses an electric wheel chair to get around. She uses a communication board to spell out words. Jean has lived in a two bedroom loft apartment with a personal care attendant for the past six years. Before that she lived for twenty five years at the county nursing home. I met her about twelve years ago when efforts first began to move her to the community. The people involved in Jean's life felt she didn't belong there, but Jean was ambivalent. Two or three times plans were made for her to move and each time she would panic at the last minute and back out. Finally the nursing home was closing and her choice was to move to another one or to live in the community. She chose community.

Jean's feelings about living in the community continue to be mixed. She grew up in a time when people with disabilities were hidden away and she is self conscious about being out in public. It took a long time to convince her to use the wheel chair equipped city bus to go on outings. She won't eat in restaurants because she is embarrassed about "being messy" and feels other people would be offended by her presence. Even at the nursing home she took meals in her room instead of with other residents in the central dining room.

Jean had a part time job with state government for a few months after she moved to her apartment. It was her first one. After a while she decided she didn't want to go back. She wasn't interested in working. It was too stressful and tiring for her. We got the county to give us the supported employment funding so that we could hire someone to help involve her in other community activities. Jean started volunteering in a program for kids with disabilities, got involved in activities at a senior center, and enrolled in an adult education class. Family and church are the most important things in Jean's life. She is very close to her brothers and nieces and nephews. She joined a Lutheran church nearby and got involved in a prayer group.

All of her life, Jean has had periodic bouts of depression ("spells", as her brother calls them). During these times, she won't get out of bed and won't eat and she has difficulty using her board to communicate what's going on. This happens about once a year. But it can take months each time to help her get back on solid ground again. During these times Jean would quit everything she was involved in and we would start over again when she felt better. Medication helped some but didn't turn things around either. One year, her brother that she was closest to died and this was devastating to Jean. She grieved intensely for months. We were at our wits end trying to figure out how to help her cope. Finally we got the minister from her church to spend time with her at home and this seemed to help her heal.

Jean is very dependent on her attendants for physical assistance. There is very little she can do without help. She has three people working for her—one who lives in, one who comes in during the day and one who provides week end respite. Since Jean doesn't work and her activity level varies with how she feels, Options provides for twenty-four hour attendant care every day.

Jean is a magnetic person. She has a compelling warmth and graciousness.

She can be very funny and she's very sensitive to the feelings of others. When I spend time with Jean her deep spirituality is always present and is profound to experience. She has had a hard time living in such close proximity with her attendants. She has been lucky to have wonderful, loyal attendants —some of whom have stayed for years. But it has been difficult for her to communicate her needs and to afford them the consideration and space they also need. It has been a challenge for us to maintain a stable team of attendants for Jean. She has very specific requirements and they can change, depending on her state of mind. Often her personal pain gets directed as anger toward her attendants. When she's feeling bad, she wants to fire people. We constantly struggle to try to sort out what the problem really is, to try to respect Jean's preferences and balance those with consistent care and reasonable expectations of her attendants.

These difficulties make sense when we think about her life in the nursing home. The nurse's aides came and went on each shift and constant turnover meant she didn't have to work out relationships with them. If she didn't like someone, there was always another aide to come along eventually. Also in the nursing home she didn't have control over her care, but at the same time she didn't have to depend so heavily on the same people to meet her basic needs. Jean has struggled with trying to direct her care and at the same time to treat her attendants fairly.

I also think the nursing home provided her with an easy mix of social and private time. When she wanted the presence of others she just had to go down the hall to whatever group activity was going on at the time. When she wanted to be alone she stayed in her room. Now, getting involved in activities is a big production. It means arranging for transportation, going outdoors in the heat or cold, and travelling somewhere, and then travelling back. It seems that a lot of the time Jean doesn't think it's worth the effort. She often prefers to stay put at home. But then we worry about the isolation and lack of stimulation in her life. We've been trying to think more about ways in which people can come to her and also to find things compelling enough to make her want to go out.

About a year ago, Jean had a serious health crisis. She has always had trouble with eating and drinking. Her disability causes her to choke easily and to have difficulty with swallowing. She weighed about 95 pounds when she left the nursing home and she was always a tiny person. Eating was always an aversive activity for Jean and a continuing source of battles with her attendants. We would pressure them to make sure she ate and drank enough and they would fight with her to carry out our instructions. Last summer she came down with a series of intestinal infections that she couldn't seem to shake. Food became an even bigger issue as her weight dropped steadily. She was hospitalized twice. But even when the infection cleared she refused to eat and drink. Her weight continued to drop and staff from Options would regularly come in to feed her in order to avoid the battles with attendants.

In the fall Jean was in the hospital again. She weighed 62 pounds at the time. Her doctor recommended that she have a gastric tube put in to insure adequate nutrition. He said she could still eat normally when she wished, but she wouldn't have to depend on that method to stay healthy. Jean was in agreement, but I was sick about it. All I could see was our failure in helping Jean maintain even a minimum level of health. She was starving under our care. Her doctor was wonderful and helped us to make peace with this course of action. He explained that for many people in Jean's position there was no pleasure in eating. It was just a hassle and that with increasing age, muscle control would get worse and the risk of choking could increase. Jean had the surgery and then went to a nursing home for several months to recuperate and to stabilize her weight. We had her attendant spend eight hours a day there to give her extra assistance. Another problem for Jean was that with her illness she was too weak to use her board to spell out words. Communication, which at the best of times was laborious, became almost impossible. We worried that once Jean was back in a nursing home she wouldn't want to return to her apartment.

Jean's health improved steadily in the nursing home and amazingly, she talked constantly of wanting to go back to her apartment. For the first time she seemed to really value being there. Jean has been home about eight months. She now weights almost a hundred pounds and her health is good. She doesn't mind the tube and has no interest in eating regular food. It's more challenging for us, because attendants have to be specially trained which makes filling in on short notice more difficult. After years of trying out different communication devices, Jean recently got a computerized system with a light reader. She is in heaven! Words that were locked inside are pouring out. She has started writing her life story. She has a great team of attendants right now who are committed to her. Lately she's been talking about firing two of them and we're trying to turn that around. A few months ago we talked with Jean about moving to a co-op. We thought she would enjoy the sense of community and she could develop relationships with people who lived close by. The co-op had regular meetings and social events. There were opportunities to get involved in a variety of

ways. Jean was interested. We waited for an accessible place to open up and she interviewed with co-op residents. They accepted her into the co-op and at the last minute Jean changed her mind. She said the apartment was too small and she was uncomfortable taking the risk of moving.

Jean seems pretty happy right now and her health continues to be good. She spends most of her time at home with attendants. Church and family are still present and important in her life. The balance always seems a bit precarious and can change from week to week. We constantly have to temper our expectations with Jean's willingness to change and try new things. Is her life any better than it was in the nursing home? Does she value her freedom and a home of her own? Or was the cost of losing the predictability of a familiar place too great? The answers vary, depending on the day you ask. Jean's expectations for her life are limited by her history. We continue to offer her new opportunities. Sometimes the answer is "yes", but just as often it's "no, thank you".

August, 1991 —Gail Jacob

Jim

Jim is a big man with light brown curly hair and a wide smile that lights up a room when he's happy. To people who don't know Jim, he can be pretty scarey when he's upset. He doesn't use many words. He's hard of hearing and uses a combination of gestures, sounds and signs to communicate. When he's angry he yells and waves his arms. Jim also has mild cerebral palsy which affects one side of his body. His favorite mode of transportation is a three wheeled bicycle.

We met Jim about seven years ago when he lived in a group home. Before that he lived most of his life in institutions. He wanted to live in an apartment and was referred to Options for services. He had a reputation for difficult behaviors and a bad temper when he got angry. The story was that when Jim moved from one facility to another (which was fairly often) he was usually transported in a sheriff's car.

We decided to set Jim up in an apartment with Tom, another man we support who is deaf. We thought they could both use sign to communicate with each other. They met and were agreeable to the plan. Jim moved in to Tom's apartment and it was a disaster from day one. They hated each other. They fought constantly. Obviously this was not going to work. We moved Jim to another apartment and spent the next eight months struggling to figure out how to support him.

Jim was a mystery to us. It was clear he needed a lot of support and we were uncomfortable with the idea of his living alone. We considered a paid roommate, but it seemed clear he couldn't tolerate anyone else living in his space. Jim could not tell us in words what he needed but he made his unhappiness known. Jim kept all his possessions in boxes piled by the door. Staff would come over every day and unpack the boxes, put his clothes back in drawers, hang the pictures back on the wall and the next day everything was back in boxes piled by the door. During those months Jim was upset all the time. He would storm into the office raging and yelling and nobody could figure out what was wrong or how to help him feel better. All we knew was we weren't getting it right for Jim.

As we continued to not get it right, Jim's behaviors got more intense and more pointed. Instead of boxes piled by his door, we were finding his possessions in the garbage dumpster behind his apartment—his t.v., his stereo dismantled and junked. Then he started attacking his apartment, destroying things and smearing feces on the walls. Maybe Jim didn't have the words, but the message was loud and clear: "I'm unhappy, I don't like it here!" We spent a lot of time running interference between Jim and neighbors, pacifying the landlord, trying to calm Jim down, and agonizing over what to do. There was a time where I thought, "This isn't going to work. He'll have to go back to the group home." But as much as I would periodically entertain the idea, I knew we had to keep trying. That we were being challenged to be more creative in our approach and to press harder to unlock the mystery of Jim's unhappiness.

We continued to struggle with different possibilities. We invited a behavioral consultant in to help us. During one brainstorming session we were talking about the paradox of Jim's need for lots of support and at the same time his need for lots of personal space and control. We then hit on the idea of a "paid neighbor"—someone who would live close by and who would provide day to day companionship and support, but who would also allow Jim the space he needed. The person would have regularly scheduled time with Jim that he could count on, but also would be flexible enough to respond to knocks on the door and phone calls when necessary. It seemed worth a try. Soon we hired Kathy to spend 15 hours a week with Jim and she moved in down the street from him. It was a match made in heaven. They loved each other and Jim seemed to change overnight into a buoyant, smiling, happy man. It was dramatic and moving to see. Kathy's role was essentially to hang out with Jim and to offer the security of a relationship and a consistent presence in his life. She also acted as a bridge to the community and an interpreter of his behaviors to neighbors and others who came into contact with Jim.

As Jim's sense of security increased, his endearing qualities quickly emerged. He is incredibly good natured, warm, friendly and generous. He inspires fierce loyalty in everyone who knows him. And he is known by many people in his east side neighborhood. He is a familiar fixture in local restaurants and he is greeted by dozens of people as he tools around on his bike. He lives in a co-op apartment now and neighbors make a point of looking out for him and letting us know when there's something we need to do for him. He has three jobs—one in a bagel shop and another at a university fraternity house. His boss at the bagel shop was so crazy about Jim that when he opened a restaurant he asked Jim to work there too. There's a funny story about Jim and employment. When we met Jim he was at a sheltered workshop where he had been for years and years. They said he wasn't employable because of his behaviors. Yet without their knowledge, Jim had gone out and gotten an evening job at a local pizza parlor where he hangs out. So he was unemployable during the day and working in the community at night!

Jim has also reconnected with his family in Milwaukee. When we met Jim, they wanted nothing to do with him. They were terrified of his anger and didn't know how to communicate with him. With Kathy's persistent encouragement, they invited Jim home for Christmas one year and the visit was a great success. Now he visits on holidays and talks to them on the phone frequently. His pride and joy are his twin nieces whose picture he proudly carries in his wallet.

Jim's presence brings joy to those who know him. His smile and gifts of fresh warm bagels can brighten our darkest days. He has also been one of Options' teachers. He taught us about not giving up—to keep trying until we get it right, about seeing behavior as communication, about the importance of being flexible—that if something doesn't work, change it. He taught us the importance of shaping services around who people are, rather than making people fit into programs and slots.

Now, seven years later, Jim doesn't need a paid neighbor anymore. Kathy and Jim continue their friendship and see each other almost every week. Jim gets along well with a few hours a week of support from his community support worker at Options, his friends, neighbors and co-workers. He still has his ups and downs like all of us, but he seems secure in knowing that when things go wrong there will be someone there to help out.

August, 1991

–Gail Jacob

Ordinary Moments

Helping people to establish and keep their rightful place in community life shapes associations based on the everyday rhythm of people's lives. In the context of a long term relationship, support staff share shopping trips, banking and bill paying, cleaning, letter writing, visits to the doctor and the hospital, and holiday preparations. Some encounters are brief and businesslike; others are social occasions. Some contacts are clearly focused on assistance; other meetings blur the boundary between helper and friend. Every shared moment offers each person the possibility of coming to know the other a little better.

New awareness may break through routine activities.

"I guess we're equal now."

As I sit in [the sheltered workshop's] parking lot waiting for Donna I wonder if there's any word about her leaving the workshop. They told her in October it would only be a couple of weeks but here it is February and there's no word.

As Donna comes out the door and looks around for my car I'm curious as to what she's got planned for today. I never know for sure - only that it's never the original plan.

"Well, hello Mitsy. I'm pooped!" she says as she gets in the car. "Say do you think we could stop and pick up some groceries on the way home?" I laugh to myself and tell her sure, no problem. I remind her about the seatbelt and she, as always, lets me know what she thinks of it. As we're driving away I ask her where she'd like to get groceries this week.

"Oh, Kohl's I guess. You know it's been a while since I've been there and, by the way, we need to talk about something after we finish shopping."

When we arrived at the store I asked Donna if she knew what she needed. "Oh, I'm not really sure," she said. "I didn't have time to shop last week but I'll know what I want when I see it. Say, you wanna grab a cart as long as you're not doing anything?"

As we go up and down the aisles Donna points out what she needs and I put it in the cart. We finally finish and head toward the checkout when Donna sees someone she knows. We get in the aisle and she begins to chat with her friend.

Suddenly I feel like an intruder in Donna's life. Part of the system which Donna struggles against so much of the time. Asking every few months to try it on her own but coming to me within a few days for assistance in some way.

As I stand there daydreaming about how it would be great if Donna could either accept me - the system, or be as she puts it "on her own", I realize Donna is talking to me. She starts laughing and asks where I was. I tell her I guess I was daydreaming and ask what she was saying.

"I said I'd like you to meet my friend, Bill. I've known him since the old [activity center] days."

I say hi and start to introduce myself when Donna says, "Bill, this is my friend Mitsy."

We chat for a couple minutes but again my mind is wandering. Donna has called me a friend and I'm thinking how much better it feels than counselor or some of the other things Donna has called me in the past. We finish up at the store and start toward her apartment and she tells me that the new key she got for her apartment doesn't work. "I'm sure it's the key this time and not the wrong door."

Curious, I asked her what she meant by the wrong door and she went on to explain to me that one afternoon she had come home from work, went in the wrong apartment building and had spent twenty minutes trying to get in someone else's apartment.

I laughed so hard I cried and then I told her I finally had something on her - so she couldn't bring up the time many months ago when I forgot to pick her up at work. She agreed and said, "Yeah, I guess we're equal now."

I think Donna may have meant to say we're even now but for once her slip of the tongue seemed to fit better. For the first time I actually felt equal instead of like someone Donna felt she needed to struggle with for control of her own life.

February 1988 –Missy Fizzell

Shopping with David

David had wanted to buy a reclining chair and he had plenty of money in his bank account, so I agreed to go shopping with him. Over the weekend he had gone to American by himself and had a look. He said he had a chair picked out.

We went to American first. David was examining his first chair when a salesman latched on. David plopped in chair after chair exclaiming, "Not soft." He ignored most of the salesman's drone about the quality of each chair and which chairs were good for "slightly built people".

"I want something soft," David ordered.

"Well," the salesman explained, "the chairs are all firm when they're new..." David didn't care. He wandered away.

"I want this chair," David said. My stomach turns - $500.00. Does TV Lenny *need* $500.00 more dollars?

"I could probably get it to you tomorrow. I'll have to check."

"Tomorrow," said David. "I wanted it today!"

"No, no, I couldn't do it today. Maybe tomorrow, have to check."

They debated for several minutes while my mind raced in panic. $500.00, $500.00 it screamed. "Go check," I told the salesman. Phew. Now I could talk to David without the ominous presence.

"David, I know you are a good shopper. Wouldn't you like to look at a few other places?"

"Well, let's see what he says," he replied.

The salesman came back saying he couldn't get a delivery till Wednesday. David obviously felt put off. "Come on," he whispered to me. We snuck away leaving the salesman looking dumbfounded.

In the car David complained that they hire delivery people to deliver furniture and if they can't do it they shouldn't hire them. I tried to explain, but realized David would be angry no matter what I said. Besides, it saved him from contributing unreasonable amounts of money toward TV Lenny's empire.

We went to another furniture store where the salesman attacked virtually as we walked in the door. He, again, blabbed of the merits of each chair and David tuned him out so he turned to me. "This one is a Lane chair. Are you familiar with Lane chairs?"

"I'm not 'into' chairs," I told him. He actually hesitated, but then went full steam ahead. I was getting really aggravated because salespeople tend to have this knack of directing their spiel toward the person they believe is in charge. David was buying the chair; it was his decision. I wanted to help him make a wise choice, but I really had no say in the matter.

"This chair has a remarkable feature," the salesman told me.

"Don't tell me," I said. "He's buying the chair." I pointed toward David.

"It has these screws on the bottom, so when the chair gets older and the springs soften you can just tighten these screws and it'll be like new."

"It has screws? This chair is going to fall apart?" said David peering under the chair.

"Well, no. It should last a long time..."

"I don't want no chair that's gonna fall apart," said David.

Realizing his mistake the salesman turned back to me. I tried to get this look in my eye. You know, the one that says, "Don't talk to me, I'm not buying this chair." It didn't work. David was between us, flipping a foot rest up and down. Talk to him I glared! No luck. I tried to look away so he wouldn't talk to me. First, I just diverted my eyes. No luck - he's still staring and talking. I put my head down. I turned completely away from him. Still he talked to me.

Eventually, David picked out a moderately priced chair that he was pleased with. It didn't have screws on the bottom - he checked. It didn't swivel but it rocked. He liked the color as long as I thought it would go in his living room. The best feature of the chair was that it was David's choice.

May 1990 —Gwen Schmidt

Familiar activities create occasions for remembering parts of a person's identity that can be forgotten in difficult times.

Wanda's Lunch

I went to Wanda's last week to take her out on one of our semi-regular lunch dates. I had been looking forward to it, for going out with Wanda means having an adventure. I always expect the unexpected, and when we're together am warmed by her generosity and charm.

But this day things were different. Wanda has been confused lately. She has good days and bad, and this was not a good one.

I called ahead so she would know when to expect me, but it still took twenty minutes and a phone call from the office for her to let me in. We then spent half an hour searching through piles of junk mail, photographs, magazines, half-written letters and coupons for her bus pass, but had no luck.

By now I was quite hungry and Wanda finally agreed we could go. With her purse in one hand and camera in the other, we made our way to Pizza Hut. She'd, for some reason, been holding that camera since I got to her house.

It was just after we ordered our food when Wanda said, "There's no film in my camera," with a worried look on her face. Her first complete sentence I'd heard today. "I don't want to stay," she said.

"But Wanda, here comes our pizza."

"Wanted to get, wanted to get..."

"What Wanda?" I asked, as our personal pan pizzas were served.

"Not going out for dinner."

"What Wanda? We're already out for dinner." Wanda was definitely bothered. She remained quiet for a few moments, and I stared out the window as I chewed, my efforts to make small talk fruitless. This was about as far from a typical lunch with Wanda as I could have. I felt lonely. I felt like Wanda didn't know who she was, and neither did I.

"Not going out for dinner," she said. "Not going out with you any more." She refused the breadsticks I offered. "Not going out again." Why was she mad at me, I wondered?

"I wanted film. Need to get film. I need a picture of us eating dinner."

That is what it was. "Sorry Wanda. I didn't know you wanted film before we ate."

One of the many ways Wanda expresses fondness for someone is to have pictures taken together, and though I've known that for years, I hadn't caught on this day. I hadn't understood all of what she was trying to tell me.

Wanda was confused. In some ways she was not her old self. But a lot of who Wanda is did not - could not - stay hidden for long, even in her different state of mind. Even feeling like she did, what she wanted most was a picture of us eating together. Perhaps next time I'll catch on sooner.

October 1989 —Peter Bazur-Leidy

BEST COPY AVAILABLE

People need invitations to share their talents as much as they need counseling or assistance with balancing their checkbook.

"I haven't played since one of your last visits"

I buzz #423.

"Hi Beulah, it's Leslie."

"OK, come on up."

On each visit, that's how our conversation begins.

I enter the elevator and push 4th floor. It's become familiar by now. Up I go until the elevator comes to its abrupt stop. I exit and begin winding my way around the long sterile halls of [the public housing unit]. A walk that leaves me feeling hollow and cold. One that Beulah makes two or three times each day as she moves about her life to her "places", which offer some measure of comfort and recognition... belonging. Serving meals at the Senior Center, an eager wait by the mailbox...perhaps a long overdue letter from Patsy, or an ice cream cone at McDonald's.

Beulah's door, #423. Distinctive on the hall with its cardboard sign reading "Beulah's Sewing and Alterations." I knock. The door opens to deep blue eyes, a lavender tam, and a welcoming "C'mon in. Hello, hello."

'Hi, Beulah. How are you?"

"Fine, just fine. Lord knows I'm never sick, dear. Oh and things are looking up. Would you believe I've made $18.50 in sewing this month?"

Beulah joins me on the couch and begins an animated conversation about her sewing projects. "Mrs. So and So wanted me to let out this dress for her. God didn't mean for us to eat like gluttons. Seems to me she should pray to the Lord and ask for a lesson in moderation," says Beulah, as she rolls her eyes in disgust. I take notice that she has done the alteration anyway, but not without charging a dollar more than she usually does for her work. I guess gluttony has its price today. Not that the dress owner can complain. Beulah has done a precise job of letting out the seams and reinforcing them with that plastic thread she likes so much... "It holds up just fine over time."

"Are you listening?" asks Beulah. My mind snaps back from its wandering. I always feel filled with more questions than answers when I visit Beulah. Yet, after each visit I feel like I have learned just a little bit more about who she is and where she comes from.

"Yes, I'm sorry, Beulah. I was just admiring your work." But, Beulah's mind is wandering now and she begins to hum to the gospel music constantly pouring out of her radio. The next song is one I'm familiar with, "The Old Rugged Cross", one of Beulah's favorites.

"Beulah, I haven't head you play your piano in a while. Looks like your bench is a little dusty."

"I haven't played since one of your last visits," she says.

"How about your rendition of "The Rugged Cross?" Beulah's eyes light.

From behind, I watch this sixty-nine year old woman, with a history difficult to imagine, dance with her aging fingers on the keyboard...pouring her heart...and soul into her favorite melody. The song over, she swings around and smiles before asking, "Would you like to hear another?" I nod yes and Beulah's off on another journey.

October 1987 –Leslie Wilmot

Passing time with people in stressful places provides a vital kind of support and can deepen appreciation for a person's capacities.

Gumption, Humor, Adversity, Tenacity, Love, and Other Assorted Ingredients

I'm sitting with Jean in her room at the hospital. It's Monday afternoon and she's been here for a little more than a day. She could "eat a horse" - so far they haven't fed her a thing that hasn't come from a bag hanging on a pole. The nurse says tomorrow or the next day she'll be able to eat.

She seems to be in possession of at most a pint of blood and they have attempted to draw a quart so far. It's a wonder it doesn't come out pure glucose. Poked, pried at, punctured, pictured, and peered into - U.W. Hospital doing their thing. Jean grimacing, grumbling, smiling, patient with her tormentors, joking, frustrated, loving and hopeful.

I leave her to go to the cafeteria so she can quietly picture making healthy new blood for them to put into test tubes. Her frail arms have almost no places left. They still don't know why the diarrhea or why her hip is in so much pain. But it isn't from a lack of testing. With a sense of hope that the next result will give them the correct picture, Jean waits through all of this.

Jean has faced a difficult year and a half in which most things seemed to work out in ways very different from expectations, and too often badly.

And now she's in the hospital again and I sit next to her telling her I'm glad she's here and that this will turn her health issues around. In reality I feel less and less confident. The last blood test showed something shockingly low and there was an immediate order for a blood transfusion. I joke about the hospital owing her some. The blood is hooked up. A very nice intern is going over all the information saying she doesn't understand this result. A second intern enters saying that they think the lab made an error and the test is being redone. Both interns leave - vanish really. Jean announces that she wants to go to a different hospital. I pat her arm.

September 1990 —Ellen Backus

Sharing a new kind of activity with someone can lead to a new appreciation of the other person's world.

Crashing Dean's Retirement Party

For several months Al had been lamenting the fact that one of his favorite co-workers, Dean, would be retiring sometime this year. I wasn't surprised, then, when he called last Tuesday to announce that Dean's retirement party was the next day. Al enthusiastically tried to convince me that it was absolutely necessary that I attend with him. He had grown accustomed to Options' staff accompanying him to holiday parties at work as his "date". Guests were expected at these parties but I was certain that this event was only for the staff who had worked with Dean. Al mentioned something about a picnic, but as usual he was pretty vague about the details of where and when. He assured me that Karen at the Northport office could fill me in on the specifics.

As I reached for my phone book to search for the number, I immediately cursed Missy for running off to a training event and leaving me to deal with what I assumed was an unpleasant duty. Since Missy or Kim had gone to parties with Al in the past, I didn't know any of his co-workers and my thoughts quickly turned to plotting how I could get out of having a meal with this group of total strangers. Maybe one of them could pick Al up and take him as they had done in the past, or at worst, I could pretend to be too busy and just drop him off.

Well, my first plan of action was immediately nixed by Karen who started off by apologizing that everyone was too busy to come and pick Al up. She certainly hoped that we could help Al get there (which was lunch at Imperial Gardens, not a picnic) because she knew Al really wanted to come. OK, on to plan B. Al was obviously disappointed when I explained my intent to drop him off at the restaurant and pick him up later. He reiterated his pleas that I attend with him, but I remained

noncommittal.

As I was walking Al to the door the next day, we met up with Ray, the bookkeeper from the Milwaukee office, who greeted Al and introduced himself to me. I immediately saw an opportunity to make my escape. "I was just dropping Al off for the party," I explained. "I guess the two of you can walk in together now."

This obviously was not going to be easy because Ray responded, "Oh, no, why don't you join us? I'm sure you're welcome. In fact, we'd love to have you," he added with enthusiasm. "If you're sure it's no problem," I mumbled, realizing by now that it would be rude of me to refuse this friendly invitation as well as disappoint Al. Besides, any excuse I offered would be an outright lie since I actually was free.

So, the three of us proceeded into the restaurant. To my horror, I soon realized that we were the last to arrive, and twenty pairs of eyes observed us as we took our places at the table. I was greatly relieved, however, to see three chairs left in close proximity - I wanted to stick close to Ray since he was directly responsible for getting me into this. Al, of course, found it necessary to draw even more attention to my presence by introducing me to most of the other diners. Everyone at Northport/ Packers Apartments now knows me by my alias, Judy Nichols. Soon their attentions were diverted to the menus, however, and Ray pointed out that we could order anything we liked - the company was picking up the tab. Hmm, this may not be so bad after all, I thought. Who says there's no such thing as a free lunch?

Well, I could only hide in my menu for so long, and I soon found it necessary to converse with the people around me. My neighbor to the left asked me if I knew Betsy Shiraga and we launched into a discussion of supported employment and people he had hired in a previous job. Al talked about his brother and his upcoming vacation and everyone listened with interest even though they've probably heard about it several times already. They told me what a hard worker Al is and how much they enjoy working with him. Ray seemed to find a way to make a joke about almost everything that came up. There was much laughter and good feeling between these people. I soon realized I was enjoying myself in spite of my initial discomfort. There was food, the presentation of Dean's gifts, several speeches and before I knew it two hours had flown by. Two hours during which I came to understand why Al likes his job so much.

It was obviously difficult for Al to say good-bye to Dean as he gave him a big hug and snapped a final picture. Al was very quiet as we drove back to his apartment and I thought about what Al's retirement party might look like.

"It was a good party, right Judy?" Al asked as he got out of the car. "Missy doesn't know what she missed."

"No, she doesn't Al. I'm really glad I came."

May 1989 –Julie Nichols-Younes

"I hope everybody likes spaghetti"

As I walked up the steps to Eileen's apartment building and glanced at the doorbells I cursed under my breath. "Why doesn't she have her name on here, damn it. I can never remember which bell it is! The ones that are marked aren't in any numerical order either. Oh well, let's try this one..."

Eileen had been hit by another car and this time had suffered more than the usual bruise - her leg was broken. I had promised the week before to come for a visit and bring dinner. I knew Eileen was a very active person and being temporarily grounded was going to be tough; she was already complaining about not being able to go to work. And now here I was on her doorstep with my bread, spaghetti and sauce, grumpy from another crazy Team 1 day. Lucky Eileen.

Well I buzzed three times and no one answered. Wrong buzzer? No one home? No. I guessed that the TV was probably on and so Eileen just couldn't hear the buzzer. Eileen is a little deaf and so her TV tends to be loud.

"Oh, well," I thought, "there's a phone booth down the block - I'll call." After two rings came the familiar "HELLO!?" with the TV blaring in the background. "Turn down the TV Eileen!" I yelled. "It's me, Amy. I buzzed you and no one answered."

"Well, Ken, she's here. Go open the door," she screamed at her boyfriend. "Oh, no, I had forgotten about Ken and had only brought two rolls and a small jar of spaghetti sauce. "OK Amy, Ken's at the buzzer so you can come over now," announced Eileen. I put down the phone to run back to the apartment and noticed the bag lady on the sidewalk eyeing me suspiciously. Hadn't she ever seen anyone scream at a phone before?

Ken let me in and I made my way up the stairs. The first thing I noticed in Eileen's apartment was how clean it was. Ken was apologizing for not hearing the bell as I walked into the living room. There was Eileen, leg in a cast, lying on the couch. I gave her a hug and she began recounting the most recent of her street crossing mishaps. She really didn't look too bad considering this was about the tenth time she had been hit by a car.

I noticed Eileen's friend Sandy sitting in the next chair. "Well, I guess I will need to run to the store for more food," I thought. Eileen and I talked a little more but I was hungry. "Eileen, I forgot something at the store so I'll just run out and get it," I said. "OK," she replied, "but take my keys so you don't get stuck outside again."

I ran out to my car and zoomed to Sentry, my stomach growling the whole way. I grabbed more spaghetti sauce and bread and flew back to Eileen's. I let myself in and climbed back upstairs. As I opened the door I saw Sandy setting the table. Eileen hobbled out with her walker. "I hope everyone likes spaghetti," I said. Eileen and Sandy nodded yes.

I made the dinner while Sandy and Eileen kept me company in the kitchen. Ken was watching a movie in the living room. We set an extra chair at the table for Eileen to put her leg on and soon everything was ready. It seemed like I was not the only one who was hungry as we polished off all the food I had brought. "That was great Amy," said Sandy. "Yes, vegetarian wasn't it?" questioned Ken. "You just leave those dishes," called Eileen as she made her way back to the living room. "Shelly, my cleaning girl, can do them tomorrow."

Eileen had recently acquired a cribbage board so she, Ken and I sat down to play a game. They were both pretty good considering they had just learned the game. The contest was close but I finally pegged out. By the time we had finished I realized I felt very relaxed. I had had a good evening with friends and my grumpiness had subsided. My mind was off of work and all the things I had left at home undone.

Thanks Eileen - and Ken and Sandy. Let's do it again real soon.

May 1988 –Amy Lutzke

Off to the Races

The day I had dreaded had arrived and stared me in the face. After travelling to a wedding the previous day, what I wanted to do on this Sunday night was to stretch out on the couch and casually read the paper. But it was June 18, and on this day I was to go with Doug to Angell Park Speedway, home of midget car racing.

Doug had been talking up these races to me for several months now, but other stories I had heard, and the weeks of anticipation had created an unpleasant image in my mind of what I would experience. What I hadn't anticipated was the cost. As I emptied my wallet for the cashier to the loud roar of the cars (and we were still outside the track), I grumbled to myself that I could be abusing my eardrums with good rock and roll rather than car engines for that price.

We made our way to the bleachers and I hoped Doug's enthusiasm would rub off on me. The event began with warm-ups. After five minutes Doug asked how I liked it so far, and trying to sound optimistic I said, "Not bad, but I'm sure the races will be better." After warm-ups the cars had to qualify, which meant another three laps each for about twenty five cars. I began to realize I was in for a long night. Finally the races began. Each race was longer that the one before, and after each race the winner was interviewed. I nervously kept my eye on my watch as the intervals between each position shift I had to make an those aluminum benches grew shorter. All that Sarah had told me was coming true.

Between the starts, and laps, and accidents (at which point all cars stop, the ambulance heads out, they tow the car, get the OK, and a long process of restarting the race occurs), I watched the sun set, took in some people-watching, and thought about what it must feel like to move around the track at such speeds. I glanced over at Doug to see him smiling; so engrossed in the activity I had to smile, too. Occasionally the noise level dropped to the point where I could hear, and Doug would share with me some information about the driver or the cars. And as the action slowed, Doug looked about for familiar faces of fellow race fans.

When the feature race had ended and all the audience gathered their chairs and blankets and things, Doug looked at me with the happiest face I think I've ever seen on him and said, "Let's go next Sunday!"

At this point my tailbone is still not the same after five hours on the bleachers, my eyes still feel dusty, and the roars of the engines echo in my head. I've certainly complained enough, but Doug introduced me to something I probably never would have seen. And I admit that during that feature race near the end when the second place midget car pulled out to first, I felt myself move to the edge of my seat and join the rest of the fans in a shout of excitement.

July 1989 —Maureen Quinlan

Holidays provide many occasions for people to disclose their individual gifts.

Thanksgiving Eve

I pick up Wanda to take her to her friend Ed's house for Thanksgiving. She is packed and ready to go except for a few miscellaneous items in the frig: homemade cranberry sauce, brownies, Tommy's cat food. As I gather her packages, Wanda stops me and says, "Here Kathy, this is for you, take it." I take a card with my name on it. Written inside I read: "Here is a dollar for your treat from me and Tommy too..Thank you for taking us (to Ed's). Love you, have a good day, from Wanda, Tommy and Eddie too." As I read the card she shoves $.75 into my hand and says, "I owe you a quarter for your treat. I always give a dollar." Wanda's thoughtfulness and generosity always surprises me. I, like the others in Wanda's life, am endlessly receiving some token of appreciation: books, trinkets, bags of food. I thank Wanda for the card and we head off to Sentry to shop for her Thanksgiving meal.

After shopping, we stop for coffee. It's Wanda's turn to buy. She orders two cinnamon rolls and coffee for herself and asks me what I want. I order coffee, explaining I just had breakfast. Wanda yells at the cashier's back, "and a sweet roll for her too." Looking my way, she admonishes me, "Don't talk crazy, don't talk crazy, Kathryn. You can eat it." She gets her change and hands me the quarter she owes me for my treat. I accept. We take our seats.

Wanda loves to talk over coffee or a meal. As she begins talking, I listen, and watch her endearing movements: the way she holds her head to the side, brushes her face with the back of her hand, curls her upper lip when making a point or waiting for a response. The eagerness with which she speaks about events of the past day or week commands my attention. Wanda says, "Say, honey, I got a card from my "real cousin" Jean, in Warren, Illinois." She hands me the card and has me read

BEST COPY AVAILABLE

it. We then begin our ritual of she dictating, I writing, a second Thanksgiving letter to Jean. We finish the letter and our coffee and get ready to leave. Wanda thanks the cashier, bids him a Merry Christmas, and off we go to Ed's.

–Kathryn Mazack

Christmas with Alice

Long before Christmas, in fact nearer to Thanksgiving, Alice was busy preparing her Christmas list and asking me when we were going to go shopping. One day in early December we ventured out, Alice with her $25.00 and a list which rivals Santa's. From that money she carefully chose gifts for Katy and her husband, the security guards at Village Mall, the folks at the Beauty Parlor, the office people at her apartment, an exchange gift for Corinthians, Kathy, Jack and myself and our cats. She also managed to have enough money left over for a pack of cigarettes for herself.

Alice had fun getting Christmas cards ready and delivering all her gifts. She frequently greeted people by singing Christmas carols or saying "Ho, ho, ho." She truly enjoys the Christmas season, and although she was interested in what gifts she would receive, and from whom, she loved choosing and giving gifts to others. When her disposable income is considered, she is extremely generous and unselfish.

Alice received so many things from so many different people. She has set up a great, supportive network for herself. Her next door neighbor, Mary, gave her a huge box of Christmas cookies - six dozen. The beauty shop, Happy Endings, gave Alice $10.00. A woman at Trinity Lutheran Church gave her a pair of slippers because Alice helps her put up new posters each month. The woman at the employment agency near Alice's apartment gave her a hat, scarf and mittens set, to name a few.

But one of the greatest stories was when her resident manager brought a turkey to my house in Sun Prairie. The apartment complex was having a promotion where if you signed another year's lease, you got a turkey. Not one to miss out on anything free, Alice decided to take advantage of the deal. But on the day she signed, they hadn't yet bought the turkeys. The apartment manager knew that Alice was coming for supper at my house before Christmas and arranged to drop off the turkey there. It was great - Alice was at my house and every so often she'd get up and go look out the window wondering "where that Pat was". Then he knocked on the door and we ceremoniously carried the turkey to our freezer where it will reside until Alice's birthday in April.

The past two Christmases that I have known Alice were happy, but also stressful and nostalgic ones where she missed being with family. I sensed that this Christmas was different and better for her because she has found another family.

–Sarah Salzwedel

Nice Holiday

"Did you have a nice holiday?" people ask me. "Yes, it was very nice," I reply. But what I am actually thinking is that this holiday season was like none I've ever experienced. I saw Christmas through the eyes of not only myself and my family, but also through Hollis' eyes, and Barb's and Alice's and Kathy's and Jim's. And the priviledge of being involved in these people's holiday preparations produced in my mind's eye a mosaic of images I hope never to forget.

I hope never to forget when that silly little man at Patti Music was explaining that Professor So and So from the University recommended the Horner Melodic in the Key of C for the beginning musician and I looked over at Barb to see her face blissfully happy at the prospect of giving Tom a harmonica for Christmas. Or Tom, who, while walking through Condon Jewelers told me, "I want to get Barb something really nice, something she's never been able to have before."

I want never to forget Hollis telling me that when he moved to Madison he couldn't read or write

and now he can write his own checks. "Isn't it a wonderful thing to be able to write your own checks?" he told me. Or later in the conversation when he said, "I remember seeing a family come into the Salvation Army and the children weren't wearing shoes. Can you imagine, they didn't even have shoes on their feet. I like to help people less fortunate than I am. That's just the way I am. Some people only think about themselves and others like to give. But you know when you give, you get it back in full. Yep, you get it back in full," he said.

I want never to forget Alice standing, hand on her hip, by her little kitchen table in her efficiency apartment proudly showing me the plastic placemat decorated with holly leaves and the matching paper plates and napkins she had bought at Walgreens because, as she put it, "Yeah, I just wanted to get a little holiday cheer in here."

And then there was the day I went to pick Kathy up at her apartment and I was unhappy because I'd lost my favorite gloves that morning. Upon hearing my tale, Kathy walked into her bedroom and came out with a brand new pair of mittens. "Here, these will keep your hands warm," she said. I politely declined. "Take them," she insisted. "I have lots of mittens. I can't use them all. Here take them."

And may I never forget Jim's handsome smiling face peering out of his front door, lit up like a beacon against the early morning darkness. It was the morning of Christmas Eve and we were to spend the next three hours together in the Greyhound Bus Depot waiting for a bus to take him home for Christmas. By the time the bus arrived we had shared cigarettes and conversation with most everyone around us. And there were at least four people who boarded that bus with Jim who had assured both him and me that they would keep an eye out to make sure Jim got off at the right stop.

Yes, I tell people, it was a very nice holiday.

–Kathy Lemke

World events shape ordinary moments.

On Being a Support Worker in Time of War

It is 1:30 on January 15. Nancy and I are just leaving her appointment at U.W. Hospital. I walk up to the passenger door to unlock it for her, turn the key and then walk around to my side and get in. I notice Nancy is still standing outside, looking in at me through the window. "You locked the door Amy," she says hesitantly.

I reach over to let her in and apologize. "I'm sorry Nancy, my mind is just not here today."

"Yeah, that's what Maureen said yesterday. You're thinking about the war."

A couple days later on the morning of the 17th I stop over to pick Nancy up for another appointment. She gets in my car and as she buckles her seat belt she bursts into tears. "I had a bad dream last night, Amy," she manages to sob. She's not sure what it was all about but something bad happened to her family. She cries for awhile while I hold her hand and remind her that she will see her mom and dad on Sunday. I tell her I've been having bad dreams too and we drive quietly to her appointment.

Ron is frantic on the other end of the phone. "There were all these people at the Capitol and they were yellin' things and carryin' signs and saying bad things to me."

"Were they really saying bad things to *you* Ron?" I question.

"Well, I don't know but I'm *upset!* I can't work with all these riots around here."

I wonder how to help Ron try to work around the "riots". I wonder how long the "riots" will last. Marcia at Goodwill wonders if Ron should take a vacation for a while.

I stop over at Carol's house to help her with her checkbook and fill her pill cases. She seems kind of quiet as I count out the Lithium and Tegretol. The TV is on in the background with the volume turned way down. The phone rings and it's her friend Don. They discuss their plans for later in the day. Suddenly Carol yells rather loudly into the phone, "Oh, Don, I'm sorry. I'm sorry I yelled at you but I was upset. I was watching the television and, well, you know there's twelve of them killed over there now." She says good by and hangs up the phone. She sits back down at the table. "I know I shouldn't watch this stuff, it makes me upset. Did you know there's twelve of them killed over there now? Oh, when will this just be over?" I start counting the Mysoline.

Rita looks at me from across the table in our booth at Perkins. "So your husband, he's not going to have to go is he?"

"Go where?" I ask looking up from my menu.

"Well if they start the draft I mean, would he have to go?"

"No, he's too old, they won't draft people who are already in their thirties," I answer, while my mind turns to my twenty one year old brother.

"Yes, well I was so surprised the other day when Ricky came over." Ricky is Rita's nineteen year old son. "He got his hair cut and it was so short! Usually he leaves it long but it was *short*, so I just had to ask him 'Ricky you didn't sign up did you?' But no he didn't sign up. I don't know if they would take him anyway, without his high school diploma. I just don't know if they would even take him."

January 1991 –Amy Lutzke

Celebrating Martin Luther King's Birth in Time of War

I was looking for a date for the Martin Luther King Day celebration. I thought about inviting Carol or Helen. It would be a way to share something meaningful, connecting them with their history and neither one would likely go on her own.

Carol said, "No way, I'm not going." She's never forgiven me for the last time.

I called Helen. "Would you like to go to the MLK celebration with me?"

"Who's he?"

"He was a black leader who fought for civil rights."

"Was he the mayor?"

"Well, no. He didn't live in Madison."

"What will they do there?"

"Oh, they'll give speeches and there will be music."

"I don't want to listen to no speeches. What kind of music?"

"Gospel music."

"I hate gospel music."

"I know, you're a Motown fan. Maybe we can get together another time. We could go out to lunch."

"Yeah, my birthday's coming up next month."

"OK, we'll go out on your birthday."

Kim said P.C. would probably like to go. P.C. said yes and plans were made. Kim reminded me that I should call him several times that afternoon. P.C. moved slow and it would take hours for him to get ready. The day of the celebration was bitter cold. My mind and my heart were consumed with

war. There was another missile attack on Israel. I was filled with hopelessness and a huge knot of anxiety as I worried about my brother, my nieces and nephews, my cousins. I didn't want to leave my house, I didn't want to see people, there was nothing to celebrate. I would call P.C. and tell him I was sick. But I didn't want to let him down if he was counting on going. I went back and forth all afternoon. At 5:00 I called him.

"Hi P.C.. Are you still planning to go to the MLK celebration?"

"Well, I haven't done my laundry yet. And I'm making supper. I just put a potato in the oven. So I don't know if I'll be ready in time."

"Well, maybe we shouldn't go. I'm not feeling too well myself." We chatted awhile and caught up on each other's lives. I told him how worried I was about my family in Israel.

"I hope your family is OK. You know, if King were alive he would of spoke out against the war. He was for peace."

"You know P.C., it's really good to talk to you. It's been a long time."

"Yeah, me too."

"Why don't we go tonight? Just wear what you have on and turn off the oven. Save the potato for later."

He was waiting at the door when I pulled up. The Civic Center was packed. The smile never left P.C.'s face. He was into it. The speeches went on. For hours. I dozed. When I would glance over at P.C., he was on the edge of his seat. We sang songs, we held hands, we prayed for peace. We sang again. "We Shall Overcome". It was late when I dropped him off. I was exhausted, but somehow I was filled up too.

"I'm glad we came, P.C.. It was good to do this with you."

"Yeah, me too. I hope you feel better."

"Thanks, I think I'm a little better already."

February 1991 —Gail Jacob

Everyday Triumphs

Options works toward a vision of the commonplace: a community in which people with disabilities enjoy the same variety of experiences as any other diverse group of citizens. Staff find satisfaction in people's everyday victories over the prejudiced low expectations that drastically limit their opportunities

Common symbols of passage, like a class ring, mark a person's passage into a new stage of development.

Class Ring

A broad smile splashed across DJ's face as he raised his arm and with a great swoop through the air, brought his hand to rest gently upon my shoulder. His eyes danced with excitement as he waited for me to notice. On DJ's hand was his new class ring. Shiny, attractive, gold. A medal of his labors and struggles to learn, grow and mature. DJ will be a high school graduate in the class of "89". Today, as he proudly displayed his ring he spoke about himself living in his own home, his student job at Pizza Hut and feeling good about his work there, getting past his fear of traveling and going on a great vacation, his struggles to develop better relationships with his mother and others. DJ seemed to have a new and profound awareness of what he has already achieved and endured. As DJ spoke, I became increasingly cognizant of how important his ring was as a tangible indicator of all his accomplishments. It was as if DJ held a graduation ceremony for himself.

February 1988 –Leslie Wilmot

Letters and cards –everyday signs of respect and belonging– matter exactly because they are 'no big deal.'

Red Duke's Dearest Fan Is on Cloud Nine

Throughout the month of June, Sandy has been on cloud nine and it's all due to her hearing from someone who has been a big part of her dreams. On June 4th, Sandy received a long anticipated return letter from Dr. James H. "Red" Duke, Jr., M.D. Red Duke (for short) is a trauma surgeon and professor at University of Texas, Health Science Center at Houston and a host of Sandy's favorite TV show "Body Watch". Sandy is Red Duke's dearest fan. She loyally watches Body Watch every Wednesday at 5 p.m. on Channel 3. She has purchased three Body Watch T-shirts thanks to Kim. And I really do thank Kim as Sandy now does her laundry even more because she likes to wear her Body Watch T-shirts as much as she can. One of Sandy's biggest dreams is to meet Red Duke in person and get his autograph. I'm sure a discussion with Red Duke about trauma care and how to become a trauma surgeon would take Sandy from cloud nine to the top of the world. Someday, I'm hoping Sandy's dream comes true but for now, it's great to be on cloud nine.

July 1989 –Janet Morgan

The Birthday Card

The birthday card was simple. It contained no cute little poems or sappy sentiment. It simply stated, "Happy Birthday Donna!! Have one on us!!" Taped inside were 15 tokens to spend on shorty beers Donna purchases to "cool down her pipes" between songs at the Union House. Mixed among all the tokens were eighteen signatures.

Some of the names sparked stories in my mind. There was Earl, the sometimes cranky but lovable man who Donna refers to as her "boss". Ruthy—who Donna refers to as the ma she never really had and Jeff and Sue—the couple who made arrangements for Donna to get to their wedding in Sun Prairie two summers ago.

All of these faceless names are people Donna is strongly connected to. People who seem to accept Donna for the funny, loyal and generous person she is. They also have made a place for Donna to

sing—something all the professional people in Donna's life have tried to deter her from. We all had good intentions—we were only trying to protect Donna from possible rejection. Rejection from a place and people Donna has known for years.

April 1989 —Missy Fizzell

Some achievements depend on many peoples' efforts and draw them together for the warmth and pleasure of shared food and celebration.

Housewarming

As I rang the doorbell, the sounds of mingled voices and laughter drifted into the hallway. I was greeted at the door by Glen, his checked flannel shirt covered by a bright green Delitalia Chef's apron. "Come on in," he said. His face was flushed with excitement. "I made a big pot of chili. You've got to try some!"

It was Glen and Darwin's housewarming party - a long awaited event, celebrating their move to the Reservoir Co-op. The house was filled with faces that were both familiar and new to me. It was a true celebration - food, flowers, gifts and friends welcoming them into their new home. Darwin was in the kitchen concentrating his energies on a bowl of Glen's chili. I recognized some of the guests as Darwin's co-workers at the State Office Building. I saw Donna, Glen's girl friend who was making her debut that day at the house, on the couch, mascara brush and compact mirror in hand, putting on the finishing touches to her face. Some of the less familiar faces belonged to Glen and Darwin's new neighbors. A mom with a toddler had moved in a few buildings down and Betty, the grandmother with the beehive hairdo that I had interviewed on the selection committee. Glen was apparently in charge of the house tour. I watched him showing one guest after another every corner of the place. When his aunt Gladys and cousin arrived, he looked like he would burst with pride.

There was such an air of excitement. The house was beautiful, spacious and warm - a place that emerged from a vision of what a home should be and feel like. At one point, conversation quieted as another guest arrived. It was Tim Cullen, Secretary of Health and Social Services, making a rather grand entrance in his black wool top coat. I think a lot of us were a little uncomfortable in his presence - except for Darwin, that is. To him, he was just another buddy from work talking football scores.

My thought wandered back to those early meetings almost two years ago when the reservoir was just an idea and to the first time I heard Susie Hobart share her vision of an intergenerational community of people who were young, older and disabled. A place that would welcome families and children, minorities, people who were financially well off as well as those who weren't, the idea of creating a neighborhood in the spirit of cooperation and empowerment. She talked about the way in which design of the buildings could encourage community by having common spaces, porches, yards and gardens and a play ground. I thought about the time, energy and commitment it takes to make a vision into a reality. The endless Planning Commission and City Council hearings, meetings to hammer out every detail. I remembered the ground breaking ceremony in an empty lot with a huge gaping hole and walking through skeletons of buildings, trying to imagine them as homes.

From the first minute I heard about the Reservoir, I knew it would be a perfect place for Darwin and Glen to live. And there at the party with the dream finally a reality, I wondered whether Darwin, back in his crib at [the institution], ever could have envisioned his life today. Though none of us talked about it, I think many of us who know Darwin and his story couldn't help but think that night, about his long journey home.

—Gail Jacob

Moves away from dependent or marginal status into such valued roles as worker and adult decision maker may only come as the fruit of long struggle.

It Was Sue's Day

You could probably say that November 2 was Sue's day. She had her usual plans to go out, she was in a great mood, and it was a day she would receive her first tangible pay off for work she had been doing at [a local institution] for quite some time.

Sue had been working at [a local institution] for a long time on a volunteer basis. She had found a niche for herself where she would run errands and deliver mail for the people there. Sue often said one of her wishes was to have a paid position at [the institution], but despite Options' people talking to them, Sue talking to them, and job developers talking to them, time passed and they were unable to find funds in their 30 million dollar budget to pay Sue for the work she was doing for them.

Again time passed, and Sue had days where she didn't want to go there to work for free, but said she'd go because she liked the "kids", or because she wanted to keep busy. Job developers were talking to Sue about what she wanted in a job - a slow process that seemed to be going nowhere in finding her a permanent *paid* job. Sue continued to go to work, often feeling very frustrated about her position, and the staff's apparent lack of understanding or appreciation for Sue's contribution to "the Center" as she calls it.

Finally, one day in July, I received a call from the Personnel Director at [the institution]. He said he would like to talk to me about Sue's possible paid employment. Great, I thought –this is the opportunity Sue has been waiting for! I went, telling him about Sue and her desires. I encouraged Sue to talk to them, and to tell her job developer that this was in the works - hoping that if Sue and other support people could advocate for Sue, one of Sue's dreams could become a reality.

Things looked positive. A job description was drafted, a wage was set, and again Sue waited. Sue's frustration continued. The budget wasn't ready –Sue waited. By this time calls from other staff inquiring about the status of Sue's job had yielded the result of "we're waiting for budget approval". Sue decided she couldn't wait, and went in herself to explain her position. She simply said that she could not give her time and services away anymore. She needed to be paid, and valued, and if she could not be paid, she would be sad to leave the people she liked, but she would have to do it. The budget *was* ready - and waiting to be passed. Finally it was passed - Sue's position was guaranteed. She would be a Clerical Helper officially, and could be paid up to 20 hours per week at minimum wage.

Needless to say, Sue was happy to hear this news, and proud of the fact she had advocated for herself to be paid. It worked. Sue worked on her new job for a few weeks, until finally she got her first check. Sue had decided she wanted to cash her check, keep part, and celebrate. The smile on Sue's face, and her happiness was good to see. It's a wonderful thing to know you are a valued employee - that what you do is important, and for Sue that feeling had been a long time coming.

"I'm happy today," she said. Yes, after a long time it was indeed Sue's day to celebrate.

November 1989 –Theresa Fishler

"Don't Give Up the Ship"

On June 30th Wanda and I had a meeting with_____ from the county to begin the proceedings to dissolve [a local aency's] corporate guardianship over Wanda. One would need to know Wanda to understand the excitement, impatience, and yes, harassment that I experienced from her between this appointment and the court hearing which was held on September 21st. Apparently the process got bogged down, for the most part thanks to good ol' Dr. _____ . Well, he's another story altogether, but for this purpose, it seems that he wasn't in such agreement with the rest of us regarding Wanda's competencies and abilities to manage her own affairs with only the support of an agency that was voluntary on Wanda's part. Well, Judy finally got his medical consent, and the hearing was scheduled. (Fortunately out of this Wanda agreed to find a different physician.)

Promptly at 9:30 a.m. on the 21st, I phoned Wanda to tell her I was on my way. I had figured she probably got up at 6 a.m., got dressed, and would be calling me at home wondering why I wasn't there. But to my surprise, Wanda was in her bathrobe and doing her laundry! I told her the necessity of getting dressed immediately and to do something with her half-done laundry. I phoned back in five minutes and she was ready, except she had to do her hair. "Not the 25 bobby pin version", I silently prayed, but I told her I'd be right there. As I pulled up she was locking her door and was soon coming down the sidewalk as quickly as I've ever seen her move. She wore her brightly colored peasant style dress (which seems appropriate as Wanda loves to tell everyone of her poverty situation). Accentuating her dress were bright purple anklets, her favorite pendant watch, two pink combs in her hair, and a slip that hung six inches below her dress. As she plopped into the front seat, I noticed that the front of her dress was soaked. "What happened?" I cautiously asked.

"Well, I had to wring that whole washer full of wet laundry out," she hollered.

Wanda chatted non-stop to the City-County Building where the hearing was to be held. She pointed out her church that she has pointed out to me every week for the past five years. She told me she had been out celebrating with beer and wine the night before. She also hollered and grabbed the dashboard as another "crazy driver" pulled away from the curb in front of us.

When we reached our destination, we had a brief struggle in the restroom as Wanda stripped off her dress to remove the too long slip. She loudly informed me and the other people in the bathroom that she didn't need that slip on anyway. She had a bra on, and that old judge wasn't going to see anything she had!

We hustled upstairs to meet Judy at 10:15. Fortunately we were a few minutes early, giving Wanda time to catch her breath. Between singing songs about her cat, Tommy, talking about Mr. _____, itemizing out how she would spend her money, and informing me about her neighbor, "Augie", who eats garbage out of the dumpster and wasn't that old Judy Nichols going to do something about it - Wanda talked about her guardianship history. The names, dates, and places seemed endless. But they were all mean, deceiving croaks that she was glad to be rid of. She spoke most emphatically about, in her words, "that dirty son-of-a-bitch"[her guardian], who was the current acting guardian. I wondered if, when this was over, Wanda would continue to call him daily, as she has for the past few years.

At 10:25, I began to wonder where the other players were. I ran up two flights of stairs to find out that there had been a room change. I ran down two flights of stairs and hailed the elevator as Wanda ambled down the hall toward me. I knew I wasn't going to get her to walk down even one flight of stairs.

As we got off the elevator, there was Judy. As we talked, the "dirty old S.O.B." himself arrived. "Oh, Judy, this is my very good guardian, _____", Wanda beamed as she put her arms around him. "I love you, _____." I only rolled my eyes, thankful that Wanda was more kind when addressing him to his face.

As we waited in the hearing room, Wanda coughed, choked, and cleared her throat, a very loud

and nasty habit that this woman has. She decided gum was what she needed. She asked Judy and [her guardian] for some. She asked me to find someone in the hall who might have some. Wanda was evidently becoming quite nervous. She started to cry, but quickly regained her composure as the court commissioner entered. The entire hearing lasted about two minutes. When the commissioner asked Wanda if she agreed with the dissolving of the guardianship, Wanda sat mute. And here I had worried about not being able to keep her quiet! I nudged Wanda and told her to say yes! When the hearing was officially over, Wanda jumped up and broke into the biggest grin I've ever seen. Wanda thanked the commissioner and announced that this was the happiest day in her entire life. "I'm finally free," she said. She let out a big laugh, and said, "Don't give up the ship. Yes, that's what my good mother taught me. Don't ever give up the ship!"

Outside the hearing room, [her guardian] handed Wanda a brown envelope. Its contents, six $50 Savings Bonds and a check for $400.00. [Her guardian] had cleaned out his files. Wanda beamed! I took one last picture of Wanda hugging [him] - a shot that Wanda has many prints of from over the years.

For the first time ever, Wanda caused no fuss about not getting a ride the long three blocks to the bank. I walked a way with Wanda, then left her strolling down East Main Street toward the Anchor Savings and Loan. That $400 check would soon be cashed and Wanda would be in heaven.

"Congratulations," I called to Wanda's back.

"Just remember, Alice," she answered. "Don't ever give up the ship."

October 1988 –Alice Sosinsky

"Firsts" may call on support workers to adjust their own view of a person and to overcome unhelpful attitudes of their own.

First Vacation

Sometimes I have to really struggle to let go of my own protective nature, especially when it comes to supporting people in taking their own risks. As difficult as it is - I acknowledge the importance of this practice. It's been easier to do this when I've had the opportunity to witness very positive changes in individuals, when protective shields of our own creation are relaxed and a person unfolds into the individual they can be.

Recently, Lorraine and Vivian traveled to Florida on their first vacation together. Lorraine has traveled some with her family. For Vivian, this trip was a first; one of historic importance in the development of her own personal history.

The genesis of this vacation idea came early in the spring during a car ride home from a group Lorraine and Vivian participated in together. At first, both Lorraine and Vivian were nervously reluctant to give a traveling vacation serious thought. But, soon they animatedly brainstormed all sorts of possibilities.

"California?"

"Yeah, yeah...well, it may be too hot."

"New York?"

"That's a rip-off place."

"Where do you want to go?"

"Florida? That's pretty far away though."

"How about Nashville? I like country music. What about you, Vick?"

"Disneyworld. Yeah, let's go to Florida."

"OK, Florida it is."

That's about like the rest of the process went for planning their first vacation together. Brainstorming, feedback, agreement. As the trip drew closer all of our anxiety increased. (I tried not to show it though.) To relieve some of that, Lorraine and Vivian remained actively involved in all travel preparations. They met weekly to keep in touch about arrangements and to role play many of the new and various tasks that they would face. Though I doubt they would admit it now, their hearts held a little terror the day of their departure. So did mine.

Four days later, Lorraine and Vivian returned from a fun packed holiday in Orlando. Epcot Center, Disneyworld, Radisson Inn, swimming, shopping, dining out, music, lots of sun, spending money, souvenirs, photographs, and memories. Lorraine and Vivian returned seasoned travelers, each of them filled with stories of the places they went, other vacationers they met and socialized with, traveling glitches they overcame, and a partnership with each other that felt complementary. They also recognized the tasks or things that made them uncomfortable. Vivian wasn't thrilled with flying, it makes her queasy - next time Dramamine first. Lorraine would like to go when it's not quite so hot. These things aside, Lorraine and Vivian had a great vacation! One of the last things I heard each of them mention was organizing another vacation in the winter.

"Nashville, California, Disneyworld again? This time we need to go for longer, four days was too short."

Their next trip I probably won't need to drink quite so much Maalox.

– Leslie Wilmot

June 1988

Assistance

Assistance with everyday tasks forms the foundation of community life for people with disabilities. Providing assistance offers little status; it consists of doing with or for someone else jobs that many people avoid or get out of their way as quickly as possible. Providing assistance has the over and over again quality of washing dishes or mowing lawns: there is little sense of durable goal attainment despite the quiet satisfactions of doing routine things well. But without competent, reliable, careful provision of individually tailored assistance day–in and day–out, people with disabilities cannot live in their own homes.

Options

At Options I have to answer the phone, alphabetize, file, sharpen pencils, fill out forms, look at computer screens and print outs, get lots of mail and phone calls, sit at a desk and use an adding machine.

At Options I have to think and write creatively, work cooperatively with other people, share my ideas and opinions, figure out answers to questions and acknowledge emotional responses to events.

At Options I have to ride buses, drive my car to churches and to X-rated book stores, go to Hardee's and "The Ovens", go shopping and to every clinic in Madison, go to weddings and funerals, go to conferences, workshops and inservices, go to budget hearings and meetings with the folks from the county.

At Options I have to talk to moms and dads, brothers and sisters, neighbors and store clerks, doctors and nurses, bureaucrats and service providers, cops and attorneys, OTs and PTs, apartment managers and collection agencies.

At Options I get to do all of these things and more. Nothing like having options in your work.

November 1990 –Kim Turner

The Magic of Communication

While I wasn't there to get the facts first hand I imagine it went something like this…

Jim was in for a physical - sending him on his way the doctor wanted to obtain a stool specimen to check for any bowel/intestinal problems. Ingrid (the speech therapist) was with Jim. The nurse probably explained to Ingrid about the stool specimen collecting procedure (seeing how she was the professional with Jim), the nurse now hopeful that Ingrid would explain the stool specimen collecting procedure to Jim.

(Editor's note: This does make some sense in-so-much-as, how could a health professional who knows the ins and outs of stool specimens really explain to a mentally retarded person who's hard to understand how to go about collecting a stool specimen?)

The story could have a quick ending thinking that Ingrid would explain stool specimen collecting procedures to Jim, but no… instead, she left a note to Kathy saying… "Jim needs a stool specimen. Will you help him? I tried to explain but it went right over his head."

(Editor's note: This is now starting to make less sense in-so-much-as you might expect that the speech therapist who has known Jim for some seven odd years *should* be able to communicate as simple a concept as stool specimen collecting procedure to Jim.)

Well now, you might assume that Kathy went right off, helped Jim collect a stool specimen, took it to the doctor and the story ends. But, again no… Kathy asks me to explain stool specimen collecting procedures to Jim (part of team leader responsibilities under the new reorganization).

(Editor's note: By now I'm sure you see that this is making no sense… I mean you would surely

expect that Kathy, who spends so much time with Jim would be able to explain to him about stool specimen collecting procedures.)

Well, faced with a task that was entirely out of the realm of a health professional, speech professional and Jim's buddy of 4 years, Kathy, I immediately thought, this is gonna be tough. I mean, if these folks couldn't figure out how to get a stool specimen from Jim, how would I? There was nobody left to delegate to (I thought about asking Polly but she had left for vacation).

I thought about substituting a specimen of my stool (or possibly Carly or Lindsay's).

Finally the task was at hand, my palms began to sweat.

"Jim is here to see you," chortled Carol.

"Jim, sit down. There is something I need to tell you," I said rather cautiously.

Jim looked at me quizzically - had he done something wrong, had someone died?

(Editor's note: Ever wonder where they come up with the word stool?)

I then proceeded in graphic language (i.e., not stool) and meticulous detail to explain to Jim using pantomimes, signs, and line drawing about stool specimen collecting. Jim laughed, I laughed. It worked so well that Jim filled up all three cardboard collectors (each with two areas for specimens) with samples of his stool.

I guess the point of this story is that Jim's deficit of understanding in this case was really our fear of explaining.

August 1988 –Sid Nichols

Moving

I have to admit that I hate helping people move. I hate doing it myself, but even more I hate moving other people. It's hard work - packing, carrying, unpacking... I usually hurt myself, bang up my car and feel exhausted by the time a move is over.

I am trying to adjust my attitude about moves for people we support. People move for a lot of reasons - not all of which are positive. But frequently people move as a part of reaching a goal to have more of what they want: a bigger apartment, a more compatible roommate, no roommate, a better location.

Sally and Frannie moved in together a couple of years back. They became good friends. Everyone thought they would stay together forever. They had found their home. But, alas, things change. Sally's mental illness has made her last year very rough for her and for Frannie. Frannie, perhaps feeling a sense of "deja vu" firmly decided that she was done having roommates; the time had come to try living on her own.

It is a positive step for Frannie. She has always struggled with stating her opinion and feeling strong enough to assertively ask for what she really wants. But what about Sally, and rent subsidies, and finding the right apartment, and packing and moving, and learning a new neighborhood?

Oh, yea... that's my job to take care of those little details. The important part is that Frannie has chosen to take a new step toward her feeling independent and having a home she feels safe in.

This story isn't finished - Frannie is still in the apartment hunting phase, and no box gathering or packing has begun. Soon... though. It will have to. And when she is all settled in her new digs, I hope she has one of those wonderful celebrations to warm her new home and remind me that moving is a celebration of dreams realized, not a plot to wreck my back!

January 1990 –Kim Turner

Finding a new place can be difficult; so can assuring the assistance to pay the rent.

New Apartment?

We stepped into the apartment and the first thing Chris said was, "Wow! Look at the big kitchen! I like this place. Can I move in today?" That was Thursday, April 20th, only ten days before Chris had to be out of her other apartment. Chris wanted to find an apartment in a house, instead of a large apartment building. It has been Chris' dream to have her own house, but for now an apartment in a house was as close as she could come.

As the landlord, Greg, showed us around, Chris pointed out the flaws. "Light bulb is out. No tub, just a shower. Can I afford it? No laundry in the building. Bathroom needs to be cleaned." Still, there was an excited look in her eyes.

The thoughts going through my mind were:

-Will Greg check her references?

-Will Greg rent it to someone else?

-Will Greg fix things that need it?

-Will [the housing authority] approve it?

-Will Chris like the other tenants?

-Will the other tenants like Chris?

-Will the Brewers go all the way this year?

It wasn't until the following Monday, six days before Chris' lease was up, that I found out about Kathy's connection to Greg. Kathy knows Greg's brother Steve, and his wife Mary, who own Ivy's Market.

By now this apartment was our only hope. And Greg Ole' boy seemed to have disappeared from this solar system. I talked to his answering machine so much that the recording plays back in my mind at the oddest times - like yesterday when I was sifting through the contents of our kitty box. I think it's the creativity of the message that has such an impact. It says: "Thank you for calling. Please leave your name and number and I will return your call as soon as possible."

All we wanted to do was find out if Chris could rent the place, and if so, would he fill out the necessary forms for [the housing authority] ? Kathy went to Ivy's and used her clout to get Steve to call his brother and get on the ball. Finally, on Thursday morning, April 27th, three days before Chris had to move, a morning on which I awoke with that homeless shelter feeling in the pit of my stomach, after which I reminded myself of what Kathy, Kathy, Mary, Gail, Betsy and I had all said, namely that "This will work out… it's going to happen", a morning on which Chris awoke and probably thought, "Hey, wait a minute, the movers are coming Sunday and I don't have a place to move yet", a morning which I would later sit down and write the longest, most awkward sentence of my life which you all are hearing spoken right now, on *that* morning the voice on the other end of the phone line at Ivy's Market said, "I've got the paperwork here for you." YEAH!

I said, "C'mon Hannah, we're going for a ride." Hannah's my daughter. As soon as I'm done telling this story I'm planning to give you a week by week accounting of her first six months. Anyway, we got the lease and the "Request for Lease Approval" form for [the housing authority] and headed for Audrey 's office. I wanted her to look at it and say something like, "Yep, mm-hmm, looks fine, perfect, go for it," etc., etc. On the way I told Hannah to smile and laugh for Audrey, so she'd be nice to us.

I noticed that Greg had not filled out half of the request form, and that the lease had incorrect dates and security deposit amounts. As we walked from the car to [the housing authority] office I took off one of Hannah's socks, because her toes are so cute.

BEST COPY AVAILABLE

We were there only ten minutes. Audrey said she'd fill in the rest of the form, crossed a few things out of the lease, changed a few numbers and said, "Looks good to me." Then she played with Hannah's toes and we exchanged, "Nice to meet you's," and we left. I let out a big sigh, and Hannah fell asleep on the way home.

I called Chris on the phone later, when she got home from a job interview. She said, "I'm so excited my words are starting to twist. Have you heard of a tongue twister? You know, this is excellent. I was giving up hope. Won't that be neat, taking care of my own house? That's excellent."

Chris is now settling in to her new home. She's met all the other tenants, caught up on the household gossip, and awaits [the housing authority] inspection. And Greg? We're still waiting for him to pick up his phone.

May 1989 –Peter Bazur-Leidy

Many people need help to recruit, hire, supervise, and fire personal assistants who will work on a visiting or, if necessary, on a live in basis. Low pay and low status make it challenging to fill these essential roles.

Weekends with Bev

The process of recruiting in-home workers is one with many ups and downs. Sometimes high expectations we have of new workers are not met, and other times the result far exceeds our hope. This is a two-part story about Bev's weekend attendant position. I'm writing the first part on Friday morning, the day a brand new person - the most recent in a long line - will be going to Bev's to spend the weekend working hard and not getting much money or thanks for it. Will Bev and Donna like each other? Will Donna want to come back again? Will Bev want her to?

Since the Fall of 1988, when Pauline quit after a wonderful, stable year of faithfully working two weekends per month, the concept of "Bev's weekends" has been frightful. "Hellish" is not too strong a word to describe the ordeal, chaotic and painful for everyone involved. Seventeen different people have worked on weekends since then, some less than a weekend, most one weekend, and a couple folks reluctantly worked two or three. Seventeen people in fifteen months. And the majority of them started out planning to work regularly.

During this time, numerous discussions have arisen among staff and with Bev in an attempt to understand why Lisa, Jamie, Danna, Tina, Dawn, Carrie, Rita, Julie, Kay, Joy, Susan, Becky, and others did not become permanent. I'm not someone who generally dwells on the negative, but something has been seriously wrong here!! Each weekend that a new person worked Missy and I would dread hearing our phones ring - and on many occasions the call *was* some problem with the weekend worker, such as a sudden illness, personality conflict with Bev or her live-in worker, or any of several other crises. Once a pregnant woman went into premature labor at Bev's. Weekends like these started me wondering whether the time had come for me to get a less stressful job as an air traffic controller at O'Hare.

A few weeks ago Donna responded to an ad I placed in an eastside newspaper. We talked on the phone, but instead of interviewing with me, she met Missy, and a few days later met Bev with Alice. Donna and Bev agreed to try this weekend and see what each thinks. As I sit here this Friday morning, I'm trying to conjure up some optimism. Maybe Bev will like the fact that Donna's older. Maybe they'll hit it off because they're both from large families. Maybe Donna will see the gifts Bev has, which sometimes lay hidden. But my hopes are battling the weekend statistics of the past fifteen months. Seventeen people. Missy walks by and tells me she's taking the attitude that Donna's just plain going to work out, and she's completing the paperwork with that in mind. This intrigues me, because, while I believe in the power of visualization and positive thinking, I have been quite pessimistic and I need to cop a better attitude and approach this like Missy is.

It's Monday morning now. Neither Missy nor I received any calls this weekend. I'm dying of curiosity. Missy calls Bev around 10:00. Although Bev can't come to the phone, Missy can hear her

enthusiasm. "I love her!" Bev is saying in the background. Missy comes to my office to tell me so far so good. I'm feeling nervous now; all weekend I thought about this. I did so much positive thinking that Bev, Donna, Bev's apartment, and the entire east side of Madison surely must have glowed with a brilliant cosmic, loving, healing aura of incredibly good Karma. And now we were about to find out what Donna thought. Missy went to call her, and luckily I got an unrelated call which diverted my attention.

A couple minutes later, Missy appeared in my doorway. She was smiling. I put my caller on hold. I heard her saying "Thumbs up. She wants the job." Amazing Grace. I felt myself spinning around in my chair, my arms flailing, feet pounding, doing the kind of happy aerobic dance I haven't been moved to do since Jean hired someone back in September. The guy who called me was left on hold entirely too long.

I have no interest in trying to analyze why the weekend worked when so many others did not. I have no desire to speculate and worry about how long this will last. No, for now I'll just be content to wear a dumb little smile around for the next few days knowing Bev likes Donna and Donna likes Bev. And I'll try real hard to think of a way to spread that Karma to some other households I know.

February 1990 —Peter Bazur-Leidy

Recruitment Pursuit

I advertised one weekend to fill an open spot
Aside from one or two good prospects, this is what I got:

"Help me Peter, hurry! I want to lend a hand
I really have to start today, please try to understand.
I love disabled people, I need to find some work
The others at the shelter all tell me I'm a jerk."

"What's wrong with this poor cripple, you say his chair has wheels?
He ought to read the Bible - don't he know that Jesus heals?
His legs could be like new again, his health could be restored
Yes, he could be completely cured by turning to the Lord."

"I was working in a carnival from Maine to Louisiana
You can't call them for a reference, they're somewhere in Indiana.
These medications blur my vision, I'm not sure what they are
They won't renew my license, but I still drive my car."

Recruiting is a fun job, I rarely get the blues
With ads in all the papers, blue sheets and interviews.
And once these folks are hired, it usually turns out nice
I've not been disappointed - well... maybe once or twice.

When I am in a real pinch, I take my respite list
And dial those numbers like a good Recruitment Specialist.
Howja like to help somebody vacuum, cook and shower,
And in return you'll get a dollar sixty two per hour.
After taxes you can make a dollar twenty three
And don't forget the IRS collects it quarterly.

July 1988 —Peter Bazur-Leidy

BEST COPY AVAILABLE

The organization of community settings makes a big difference to the amount of work involved in taking care of daily needs or enjoying an afternoon out.

Waiting Around

Now that I am a Community Support Worker (CSW) it appears that my main mission is to accompany people to their medical appointments. In the last two weeks alone, I have been to the Madison Medical Center, the Jackson Clinic, and the U.W. Clinic. I have seen a neurologist, a podiatrist, a gynecologist, an ear, nose and throat specialist, a urologist, and a general practitioner.

All totaled, I have spent 50 minutes with these professionals. I have acquired a small bit of medical information during these 50 minutes. But I really learned more valuable information in 185 minutes. Which, by the way, is the time I spent waiting for these doctors (starting from the time the appointment was supposed to start). Here is a short summary of what I've learned.

The clinic least likely to be distracted in is the Madison Medical Center. Each department is in its own separate area behind a closed door. The rooms are usually small and somewhat soothing with the Muzak piping through the intercom lulling people to a state of near unconsciousness. So what if it's a 30 piece orchestra playing its version of "I Can't Get No Satisfaction", it's calming. I found the wait at this clinic to be equal to the length of a nap, which is exactly what you'll feel like doing. I would advise a couple of cups of strong coffee before an appointment here.

The waiting room in the Gynecology Department of the Jackson Clinic was by far the friendliest. The first thing you notice when you get off the elevator is the smell of freshly brewed coffee, both decaf and regular, a nice touch. But the biggest surprise in this waiting room is a huge window that actually looks outside, not into another waiting room. It's really quite nice in the 80's. As luck would have it, I was only able to spend three minutes in this pleasure palace because the doctor was ready on time. I highly recommend a visit here, but I would advise coming early so you enjoy all the benefits this room has to offer.

After having said this about these two clinics the only thing I can tell you about the U.W. Clinic is, don't go.

Next month I have three [housing agency] appointments, a Social Security appointment, and more trips to the doctor. The main thing I have learned, so far, about being a CSW is that it's a lot of waiting around.

February 1989 —Diane Steele

A Day at the Brewers

As we pulled away from Eric and Darwin's respective apartments, we thought we were off to a fun filled day at Milwaukee Stadium to watch a ball game. Needless to say, the people running the stadium must have known we were coming and decided we would be good subjects to confuse, redirect, and segregate.

Since Kathryn and I had never been to this particular stadium for a ball game, we had gotten advice before leaving as to where we should sit. Our advice was that Darwin would enjoy the game more if we sat in the lower bleachers. So, feeling pretty certain about what we wanted Kathryn stepped up to the window and asked for the tickets. The man behind the window obviously had other ideas and was quick to tell us wheelchairs go to the upper deck. Kathryn tried to tell him that wasn't where we wanted to sit, but the man was firm and insinuated he would not sell us lower grand stand. Since none of us really knew what we were doing we quietly took the tickets the man was willing to give us and set off to find seats.

As we passed through the gate we decided to check with the security man as to how we got to the upper deck. He told us we could go to either end of the stadium and go up the ramps. We then

stopped to buy food and a new hat for Darwin in order to save time and discussed the fact that one end of the stadium might be better than the other since it would be closer to the car.

We walked for what seemed a mile, at least from looking at Eric, and even stopped once to ask directions to make sure we were still on track. When finally we saw the escalator, it looked tricky, but we decided if one of us held the food the other could take Darwin up and come back to help after finding seats. Just as we were about to proceed with our plan a security guard called out, "What are ya doing?" We quickly told him we were going up, when he said he thought we shouldn't. We tried to explain that we really didn't think it was a problem but he was quicker in telling us it was. He then explained we'd need to go back a short distance to the elevator.

So, off once again, we headed out in search of the elevator. Finally after having walked almost all the way around the stadium we spotted it - a line of approximately 20 people waiting to go up to a game that started in less than five minutes.

Finally, our turn came and we stepped off the elevator in time to hear the end of the Star Spangled Banner and to see a sea of people in wheelchairs grouped around the back rows. What was worse was the fact that a good share of these people were wearing lovely yellow cutouts shaped like apples, that sported the name of their nursing home.

Finally, feeling defeated and drained, we sat down to watch the game. We watched in dismay as inning after inning there was no score. In the 11th inning we even went so far as to suggest we go, if there was no score by the 12th inning. This, however, did not go over well with our companions for the day.

By the 13th inning Kathryn and I were desperate for someone to score. We didn't care who, as long as we could go home. Suddenly, Kansas City scored and Kathryn cheered. The inning went on with Kansas City winning 4 to 0.

We made our way slowly to the front of the line at the elevator, only to be told we'd have to wait for the next ride, because we weren't part of the group. In a last desperate attempt to have her way at least once that day, Kathryn quickly said, "We are part of your group," and crowded us on.

So while it was a long and frustrating day, everyone seemed to get out of it what they wanted. Darwin got to root for his favorite team, Eric got to eat junk food all day without being nagged, Kathryn learned how the game of baseball is actually played and I got a little closer to knowing who Eric and Darwin really are.

August 1988 – Missy Fizzell

Understanding

Understanding someone differs importantly from arranging facts into a social history. Understanding gives one person a glimpse and a feeling of what it is about to be another person. So it guides assistants toward a better fit between their efforts and individual circumstances. And it provides hints about what is going on when a person's situation goes badly and becomes confused.

Developing understanding means taking care to find the sense a person attaches to words they find important. Especially when people have limited language or use language in idiosyncratic ways, this depends on time and reflection on shared experience.

"Getting Out"

Alex has often talked about "getting out" someday. This is confusing to others because Alex isn't locked up in a prison, living in an institution or even a group home. Alex did live in those kind of settings, but for the past five years Alex has lived in a few apartments in a few different neighborhoods and he still talked about "getting out". No one has figured out exactly what Alex means by "getting out", but I think it may mean Alex still hasn't found his home. After five years of living in apartments and talking about "getting out", Alex has found his home on the east side of Madison. It took a while because Alex isn't very "well to do" but he wanted to live that way. He wanted a brand new place with brand new appliances and an electric stove. Alex also doesn't like to bathe or change his clothes much and others would say to Alex, "You're going to have to look and dress better if you want your new neighbors to accept you - especially living in a nice neighborhood." Despite Alex's poverty and appearance, his day came. I went to see Alex yesterday in his new home. As I walked up the street I saw Alex talking to his neighbor next door. Later Alex gave me a tour of his place. It's a brand new place with brand new appliances and an electric stove. I said to Alex, "You're finally out now. How does it feel?" Alex, with a big grin on his unshaven face, looked me in the eye, paused a few moments, waved his hand like he always does and said, "Well it's like this way. This is my home. I'm out."

–Kim Turner

The Places

Charlie's sipping his coffee, talking. I try to follow his thoughts as they travel from past to present, from real life to imagined life. An avid movie-watcher, Charlie lives in his favorite characters' lives: caught between real life and fantasies of a life that could be. "Did you know I used to be a neurosurgeon and a lawyer? I kid you not, just like the guy on *LA Law*. These are some of my fantasies Kathleen, for real. I've got lots of stories." Charlie tells me of movies he's seen: "The movie, *One Flew Over the Cuckoo's Nest*, I was in it. In real life. That's exactly what it was like. When I saw it I was really moved. *One Day in the Life of Ivan Denisovich*. It was so real to me. The ones being dirty on the others. My God, it was just like the places. The places." With that thought Charlie begins to narrate his own life story...

When I was born I had spinal meningitis and epilepsy. Because of that I was put away after a few years. In institutions, in hospitals. After a few years I escaped. *The Great Escape*. I didn't like the guards in that movie. It shook me, it took me back. Those people being kicked and mistreated.

I grew up without a father. He left us. I didn't know about that then. I didn't understand it. It's mixed up for me. I have to go back. It's hard to get back to that now. You tried to behave and when you didn't you got talked to. I got talked to. That's why I got put away. No man around the house. No father. There was a time I had stolen and didn't realize I had stolen. At my aunt's and uncle's. They had money on the table. It was family so I thought it was OK. My mom talked to

me. I had to account for each penny. Recently, I made that comment to them. I think they heard it wrong. I'm wondering if that's why they come in and take from me. She gave me a good talking to.

We lived on farms: my mother, two sisters, Karen and Judy, and my brother. They have a big part in it themselves. Judy, we lost her in a car accident when I was at the training institute in _____. I was eleven maybe then. Mr. _____ called me up to the office to tell me about it. I cried and when I went back to the ward they said, "I bet you got it from him." They didn't know what happened.

Before the training school... when I was home and did things... sometimes you were a little cocky and you knew it. I needed someone to talk to. I was scared to talk to mom. I was never included.

Christmas and birthdays, them were the big times of the year. Playing with the cows like I did and going into the hay mound. I just remember some of the stuff when we lived on the farm. There was a hill. Boy, we loved to roll down the hill, play with the cows. It made us feel good to help out. I don't remember that stuff real good. I guess the story is more about the institution where I was put away.

The sheriff's deputy came to pick me up to take me to [the institution]. It was a big deal as a kid to be riding in the sheriff's car. I was a troubled child, always hollering. I was terrible to my mother, always fighting with her, and boy, I love that broad. That's why they put me away. I was ill-mannered. But I learned.

I was in the building with a lot of other children my age. When I got seizures they didn't know what to do with me. They didn't care. They'd kick you or douse you with a bucket of water. They must not have known what seizures were. "You're not that sick. Get up." "I'm sorry." They didn't like to have to come and help you.

You always had a best friend you did things with. Like Jackie and Perry. School was the big part why I went there. At home I wouldn't learn. We were only glad to go to school to get out of the building. Every time there was a new person it was a big deal. The new boy.

After a while, I got to like it. They weren't just bad guys there. There were some awful good aides. When you had to talk they were there. I was there five years. During that time my sister died, my cousin died, both in wrecks.

You got lonesome. You wanted to go home. We all worked. I worked in the hospital in building 4 as an aide on weekends, helping feed 'em, and dress' em, things as this. When I say I worked as an aide I kid you not. Later when I was at [a state hospital] I worked as an aide, too. There were some patients who liked me. When you walked in they'd say, "Here he is, here's our man." That felt good to know you weren't just there to help them out, but they wanted you there. That felt good. Little did they know they helped me out.

We had a movie every Friday. I think monthly we went into town to the barber shops. There was regular schooling, picnics, and things as this. There were three different farms with the place. Us guys worked in the gardens picking radishes, weeding. These are big, big gardens, not just one of your little ones. We were feeding two other places as well. I think some of the food went to a prison.

You were always glad to get visitors. One time my relatives came up and I didn't know who they were. They came walking up the playground. They took you away and that was an awful big thing.

Later, I went to [another state hospital] for ten years until I escaped. Believe me it wasn't smooth sailing, and the relatives, they were ashamed. *The Great Escape.* That's a whole other story...

July 1988 –Kathryn Mazack

BEST COPY AVAILABLE

Sometimes a moment discloses a part of what makes a person unique.

The Best Dressed Dishwasher

A while back I asked Andy what he would like to buy for himself most of all. He said, "A suit," and then asked, "When can I get one?" His answer didn't surprise me as Andy likes to dress up in style. On one occasion Andy went to great lengths to do so.

Andy's roommate, Ron, had an expensive white suit which Andy took a liking to. One morning Andy somehow managed to get a hold of this suit and went to work in style. He slipped out of the house without anyone noticing he was wearing Ron's suit. He managed this by wearing his clothes over the suit. When Andy arrived at work he went straight to the bathroom and discarded his outer clothes. Andy, by the way, washes dishes and buses tables at [a technical school]. I wasn't there but I can picture Andy coming out of the bathroom, all dressed up, a smile on his face and his head held high, proud of the fact that he's the best dressed dishwasher at work that day.

Over time, Andy did get a suit of his own, and a pin striped one at that. He's worn it on holidays, to parties, and even to Bogie's dancing with his girlfriend. Maybe even to work - who knows! Now, when you ask Andy what he would like to buy most of all - he will say "Cowboy boots," and then asks "When?" Let this be a warning to any of his roommates who own cowboy boots.

September 1987 –Janet Morgan

Pre-judgement and assigning people to roles simplify everyday contacts to the point of destroying opportunities for understanding to grow.

I Finally Got Around to Meeting Jean

It wasn't until the end of December of last year that I finally got around to meeting Jean. Oh, I had talked about her a lot. While recruiting for her, I'd often hear myself saying to a prospective attendant: "Jean is very nice..." or Jean is one of the *nicest* people..." It was a second hand opinion.

Once on a Friday afternoon she had her attendant call me. "Hello, Peter. This is Jane. Jean wanted me to tell you she'd like to meet you sometime." I said something about looking at my calendar and trying to make it soon.

Unfortunately, my timing wasn't the greatest. During December Jean had a lot of respite people, and on top of that she wasn't in very good health. Somewhere between keeping track of which attendant was supposed to come in next and trips to the doctor she made room for me.

I had an immediate impression of Jean when she met me at the door. Not only was she quite severely physically disabled, but she was probably quite retarded as well. Plus, she just didn't look very good. It is only reluctantly that I admit that the status of Jean's cognitive ability even entered my mind, but it *did* - and in the first 30 seconds of meeting her. I think that's called "prejudice".

"I'm glad to finally meet you," I said after I sat down. She began to spell something on her communication board. "I'm... beginning... to... think... that... I... can't... live... independently... any... more." She went on to describe that she'd not been feeling well and that she had been frustrated with her attendant schedule. At times I couldn't read as fast as she was pointing, and it soon occurred to me that if one of us was impaired, it probably wasn't Jean.

Her physical discomfort cut our meeting short that day, after 30 or 40 minutes together. I didn't say much; Jean had more to say. Although I could tell that Jean was a warm, friendly person (like I had heard), I left there feeling down about Jean's health and mad at myself for having pre-judged her. I wondered how many other people who see Jean assume she's less able than she is. Has anyone ever looked at Jean and chosen not to initiate a conversation or friendship, thinking that Jean would not have much to offer? I would imagine so.

A few weeks after our initial meeting I saw Jean at Options' party. She seemed to be feeling much better. I remembered her first words to me the last time we met. This time when I said "Hi, Jean," I wondered what she would say. She smiled at me and pointed to her board. "Glad... to... see... you... again... it... is... nicer... this... time." Jean's vitality was very apparent as we communicated this time.

As I recruit attendants for Jean from time to time in the future, I'll probably still say that Jean is very nice. But from now on I'll know that. I'll also know that Jean is more than just nice.

February 1988 –Peter Bazur-Leidy

Oxymoron

This is a story about oxymorons. Language has never been my strong suit. Last week I became aware of the word oxymoron. It first came up when Dr. _____ was giving us our inservice. I had no idea what "oxymoron" meant and frankly I don't even remember the context in which it was used. My next exposure to the word was Saturday as I was reading the AC/DC concert review in the *Cap Times*. Given the context, I sort of figured out what oxymoron meant but still I wasn't quite sure. Finally it all came to a head Sunday when I was reading the comic B.C. Yes, it appears that oxymoron has become a word of the eighties. It was then that I decided that I better look it up in the dictionary... illiteracy can only last so long. It seems that an oxymoron is a set of contradictory words, i.e. cruel kindness.

Anyway, now equipped with a new literary tool I have decided to draw an analogy or parallel between the word and Ron.

I'm sure most of you know Ron has been in crisis the past couple of weeks. As is usually the case, Ron's craziness is sometimes absurd, always stressful, frequently frustrating and almost never "fixable". My way of dealing with these conditions fluctuates between losing perspective and thus burning out (i.e. I am going to fix him) or venting my frustrations on others, often with humor.

The problem here, though, is that Options often serves as the arena or stage for Ron's craziness. We all become part of it. And pretty soon we all deal with this discomfort and stress by humorously venting. While venting, in and of itself is healthy, the realization is that Ron is a person and that, regardless of the absurdity of it all, Options has a strong set of values that reflect a strong positive regard for people no matter what seems to be the person's unique qualities. The stage for espousing human values conflicts with the stage for Ron's absurdity.

Here it would be oh so easy for me to tell hundred of stories about the past couple weeks in Ron's life. And they would be humorous. And my intentions would be sincere. My humorous stories about Ron seem to be a type of cruel kindness.

Here is where it all ties in. Oxymoron and Ron. It is easy to forget that given our strong values and the constant absurdity of Ron's actions, that he in no way should become the agency jester. It should never be a case of cruel kindness. I have to work on the task of maintaining that positive regard. It is only cruel, not kind to Ron, when I create a dialogue where Ron and my values compete.

June 1988 –Sid Nichols

Understanding only grows when people recognize that others contain many possibilities, some of them contradictory. The expectation that another person is one way or another filters out much of their reality.

Babies

Since Chris moved out of [a nursing home] in October 1987, she has lived in two apartments. There are thousands of apartments in Madison and babies don't live next to most of them. But, so far, Chris is two for two.

Her first apartment had thin walls. You could hear a lot through them, including the cry of a baby. Her second apartment was built as a bomb shelter, and unless you have ears like the bionic woman, or like Chris's, you'd have a real hard time hearing the baby that sometimes cries next door. Chris says she can even hear the baby when she's listening to her stereo. With headphones.

Somehow, despite living in institutions where she had little privacy, where people talked and screamed and played music and interrupted her sleep on a daily basis, a crying baby next door is too much. I've been at her apartment when the baby is crying. When I walked in the hall past the neighbor's I heard a faint cry - and upon entering Chris's I tried and tried but could hear nothing.

These two babies have been the subject of various confrontations (in the first apartment, even before the baby was born) between Chris and her neighbors.

I've had trouble understanding why. Several months ago Chris [a friend of Christine's] told me how affectionately Christine treated his children. Granted, Chris doesn't *live* next to her friends, but it puzzled me how someone who acted so lovingly toward some young children and even a new baby could say and write such threatening words toward other babies and their parents.

On the Friday before Martin Luther King Day, Betsy, Hannah and I met Chris at a dinner at the Methodist Church. The meal was sponsored by Response to Hunger, and it brought to life Dr. King's dream of all kinds of people from different backgrounds sitting down and sharing a meal together.

The three of us and Hannah sat at a table with quite a mixture of people. Looking around the room I saw people were ranging from about two months to eighty years, poor to wealthy, white, black and every shade in between.

The food was delicious and the music - piano and small chorus with folks who appeared to be mostly in their 50s and 60s - got everyone in the room clapping. There were several speakers as well, but the atmosphere, the sharing, the community in that room was really something.

It was great to be there with Chris. She had a good time and I could tell that helping celebrate Martin Luther King's birthday was meaningful for her.

Chris had met Hannah before, but only briefly. As soon as we sat down at our table she asked to hold her. I couldn't believe what I saw and heard.

"Hi, Hannah. Are you hungry? Do you think she's hungry Peter?"

"I s'pose she'll eat pretty soon Chris; she eats a lot."

"I should hold her while you eat," Chris said. "Hey Hannah, you're getting big. Do you think she's hungry?"

"Well, Chris. She usually lets us know when she's hungry. She looks pretty content right now."

Chris was a natural. She looked perfectly comfortable holding Hannah. "She seems happy in my lap. Look at all this food, Hannah. I bet she's hungry."

Betsy and I helped get the salad, pasta, fruit salad and bread on Chris's plate. I asked Chris if she was OK with Hannah. She was holding Hannah in her left arm, eating with her right - something that took *me* quite a while to perfect. I told her she was good at that; she looked like she'd had a lot of experience doing it.

"I'm good with kids," she said, and kept eating.

February 1989 –Peter Bazur-Leidy

The oppression of institutionalization robbed some people of their history. Someone who is willing to read official records meditatively may be able to reconstruct some of a person's past as it felt to live it. Someone who is willing to risk revealing self as well as the other person may be able to draw on their experience of the person to try a voice that might fit the person's style. This reflection gives voice to the possible impact of the composite experiences of a number of people the writer has known.

My Name Is Dan

My name is Dan. I was asked to write some things about my life for you. At first I thought why in the hell should I spend time trying to explain things to you... I have better things to do. But when I was offered money... hey, that's another story. Anyway I was born in 1957 in _____. Like most kids I really don't remember much about the first few years. When I was four my sister Ann was born. The first thing I really remember as a child was my parents fighting about problems I was having. I was five and still wasn't able to talk too much, I still peed and shit my pants and I spent lots of time staring into space. My mom said I was sensitive, my dad said I was nutty. My folks fought all the time about me. My dad never could deal with the fact that I wasn't going to be "normal". He told my mom that he wanted a child, not a monster. When I was six my dad left his wife and family high and dry. No one has ever heard from him since then.

My mom, facing the challenge of raising two kids with no money, didn't know what to do. She tried working for a while, but finding people to take care of me was hard. I was supposed to be in school, but the school in our town told my mom that they really couldn't have me in school. I wouldn't learn anything and I would take away from the other kid's education. At the age of seven my mom gave up. She sent me to a foster home. I'll never forget the day that she took me to [a foster home]. It was a sunny day in October, the leaves had begun to fall from the trees. She took me up to the door and we both began to cry. She told me she'd see me again and to be a good boy for Mr. and Mrs. [foster parents]. As she walked down the sidewalk to go catch the bus she never turned around to wave. I knew she'd never see me again. That is my last memory of mom; her walking briskly as the leaves fall around her. I can still smell the changing season. Every fall I get depressed. I'm sure her leaving me is the reason.

The [foster parents] were quite the pair. They had three kids of their own plus six foster kids to take care of. They were a real "law and order" type of family. Anyway at seven, a kid who's been left alone can get pretty fucking angry. Needless to say, I didn't fit into the "law and order" of the [foster parents]. One day a social worker from the state came to talk to me. She said, "Dan, if you don't start behaving yourself you won't be able to live with the Anderson's anymore." Like it was my decision to live there in the first place.

Two months is how long I lasted until they sent me to the State School for the retarded. That's what happens when you try to treat somebody instead of understand them. I mean who of you were deserted at the age of seven.

The state school was a large brick building in the country. I was sentenced when I was seven and condemned there for sixteen years. The whitecoats who ran the place were all fat men who smelled of gin and cigars. They didn't give a damn about us kids. As long as it was, "Yes, sir, in bed by 8, eat all your food, no fighting," us kids got along with all the whitecoats.

One whitecoat who I really liked was a man named Gil. He was the only person in sixteen years who really cared about me. I think if he would have been my father all this shit about being in retarded prison wouldn't have happened. Gil and I used to go on walks and fishing trips. He taught me checkers and cards and would bring his hunting magazines in for me to look at. One day Gil didn't show up for work. Nobody ever told us why but rumor has it that Gil had a heart attack and died. It's fucking ironic that the one person in my life who ever loved me died and I had to find out about it from a patient on first floor.

Talking about the times I was beat (over 40 times), raped (3 times) at the prison is something I still

haven't been able to deal with. It makes me so mad... I don't want to go into it, other than to tell you it happened.

When I was 23 some folks came to visit me. They said that I was a priority to them. They needed me to move out of the retarded school. They said it was because they cared about me and wanted to free me. Really it was because the State was losing money having us retarded people in prison. Anyway these people talked about moving and freedom. They had plans for me to move back to _____ and live in a group home. It's funny how these workers talked of *my* freedom. To them freedom is just a word, something they haven't the faintest idea about. They have no fucking idea about freedom, they were never locked away for sixteen years. Let me talk about freedom, I know what it's about.

Anyway seven years on the outside, in and out of group homes, and finally in my own home. It's sad, but sometimes I think it was easier to deal with the walls when I was in the retarded school. The walls were visible, concrete (literally) and were always present. At night, when you wake up, the walls were always there to serve as a reminder that I had committed the crime of having a low IQ.

The walls on the outside are harder to deal with. The whitecoats are still there but now they are young women who do their nails and care a lot for me and my sad and pitiful life. But it's the same story. Now they want me to live their lives, shop at their stores, wear the fashionable clothes, live in nice flats. For sixteen years nobody wanted me to be a part of anything and now folks are chomping at the bits to get my life back in shape. I don't want to fucking work. I don't give a damn about your rules and lifestyles. The walls are still there, you just never know when they are going to appear.

It's kinda' funny, kinda' sad. These workers talk to me about how they are trying to help by breaking down these walls for me. Sort of spiritual demolition experts. Get out your philosophical ball and chain and... bang. Break down a wall for *me*.

Well, I got news for all of you. I don't need no fucking walls broken down for me. It's you who need walls broken down. The walls don't stand in my way but the walls stand in your way. You see I know you inside and out. I look in your eyes and know you. But do you really know me?

March 1988 –Sid Nichols

How People Change

Unlike Options, typical human service programs aim to change their clients by increasing skills and modifying unacceptable behavior. Typical programs structure their client's time and relationships on the basis of staff ideas about how people change. Options' staff start from another place: they challenge themselves to discover what it will take to support each person to make and keep a place in community life. This stance gives Options staff a wide perspective on the variety of experiences that contribute to significant change in people's lives. This perspective discloses the crucial importance of choice, relationships, and opportunity.

People change as staff respect for their power to choose increases their personal fund of experiences.

From Badger Camp to Milwaukee to (?)

As I walked up to Andy's house I thought I knew what was in store for me. I was right, but then some. I knew Andy was anxious to pick up his cowboy boots at Cecil's Shoe Repair store. What else he had in mind was a mystery. Lots of everyday stuff I figured. Rightly so.

Andy appears at the front door and does his typical "hello-good-bye" routine while opening and closing the door in front of me. Sooner or later he lets me in. Andy, in his own way of greeting people, shakes my shoulders instead of my hand, asks how I'm doing and informs me I'm late. Next Andy informs me of today's doings. He wants to pick up his cowboy boots of course. He wants help in figuring out what to do with his swollen finger which he slammed in the door yesterday. He would like to write out a $10.00 to Sentry and his roommate would also like him to pay his part of the WI Bell bill. All this within minutes of walking through the door and I have a half an hour. Oh, yes, and with a bit of a prompt from his roommate, Andy pulls out a $484.00 Homestead check from his shirt pocket. I ask Andy what he'd really like to do first and off we went to Cecil's Shoe Repair store. On our way I asked Andy what he'd like to do with his Homestead check. The answer was short and simple. "Cash it and spend it," Andy replied. I mention the thought of taking a vacation. Andy liked that idea. I remember back to last year when I asked Andy where he'd like to go on vacation. "Badger Camp," he replied. "Of course," I sighed. Badger Camp, the only place he's ever gone on vacation, summer after summer. His horizons are expanding though. Last year, with a lot of effort in planning, organizing and coming up with the money, Andy was able to go on a different trip - a weekend in Milwaukee. To Andy, a new vacation experience. To most anyone else, a close diversion from Madison.

Now when I asked Andy where he'd like to go on vacation, he didn't say "Badger Camp". He said, "Milwaukee." At 26 years old, there is so much Andy hasn't experienced. His choices are limited - where he can go, what he can do, when he can go and who he can go with. It's all been decided for him, for numerous yet important reasons. It's changing though, I keep telling myself. This year we are talking to Andy about a Wilderness Inquiry trip. In the future when a vacation draws near, I'm hoping Andy will be able to say, "Mexico, Tahiti or (?)."

After Andy and I pick up his cowboy boots, talk to a nurse about his swollen finger, discuss home remedies, and write out a check to Sentry, I leave, and *not* half an hour later. On my way out, Andy shouts his personal farewell. "Bye and don't come back." I smile and sigh knowing he's only joking.

April 1988 –Janet Morgan

People try out change in order to pursue personal goals; sometimes with good results.

Alex Changed His Shirt

Yes, Alex changed his shirt. I think he had been wearing the same shirt since October. He had changed in September for his father's funeral, but then he changed back again to the same old shirt.

This change was in response to my prompting that it would help him to get an apartment he was interested in if he looked his best. I didn't expect anything to happen, so imagine my surprise when Alex greeted me excitedly wearing a new shirt, clean shaven and with what appeared to be freshly washed hair. I was impressed.

Unfortunately, when we got to the apartment we were unable to see it - the current tenant would not open the door. Alex's disappointment was extreme. He sat quietly while I talked to the manager, and then left to wait in the car.

His first comment was to say he didn't want to live in that place anyway.

"Why?" I asked, trying not to sound frustrated, pissed off, exhausted and at my wits end about how to find a new apartment for Alex.

Alex responded in various half sentences like, "It's like this...", "How do you like that?" "And another thing..."

I still had no idea what Alex was thinking or feeling other than his obvious disappointment about the failed visit.

So... Alex with the new shirt decided he would rather visit a friend than go home. Before I dropped him off I told him how good he looked and that I was sorry we couldn't see the apartment.

"Eh..." he responded. "Call me tomorrow."

I have to wonder about Alex's shirts. Can you imagine wearing the same shirt - a poly/cotton blend polo-style pullover - day after day for over six months? I buy clothes that fall apart much quicker than that when I only wear them a couple of times a month. It must be the washing and drying process. I never realized that was what was destroying my clothes.

Back to Alex. This clean shirt has produced a huge amount of guilt in my psyche. I'm feeling responsible for causing Alex to make such a drastic change in his life - putting on a new shirt (I mean really new - fresh out of the package) for absolutely no payback. He may never do it again. A new clean shirt is a terrible thing to waste. When I saw Alex the next day he had changed shirts again - not back to the original old one, but a different well-used unwashed shirt I hadn't seen for over a year.

June 1989 –Kim Turner

Sharing experiences with a staff person who treats you as an equal can build confidence and energy.

This Year, Nancy Was Glowing

The big day was here and out we headed to East Towne Mall to buy some clothes for the prestigious event, the Options' party. Nancy found a black sweater, black pants and new shoes that she decided she would like to wear. She was excited about this party but somewhat apprehensive also. Last year, you see, Nancy went to this same party although she had a terrible time. She held onto Amy, was extremely nervous and never went near the dance floor, much less would not leave Amy's side. Left after an hour and didn't talk to anyone. This vision all played back in my mind as she paid for the items she bought.

She was staying with me all afternoon and so the next stop was my house. She was real excited about going to the new apartment that I had just moved into. Well, we got there and ironed her clothes for the party. We cooked dinner - Friday Night Fish Fry, to be exact. We ate and Nancy

helped do dishes and put away left overs. Then I started putting on make up for the party. Nancy asked me how I thought she would look in make up so I put some on her and we curled her hair. She looked absolutely beautiful. She was glowing and really seemed to be looking forward to this party more and more. We arrived at 7:20 and the first thing she did was walk around and talk to everyone she knew. And when the music didn't start at the time she wanted she told me she asked Gail when they were going to start that music. Nancy and I danced and danced and danced and danced and when I left she was still dancing. And I really had fun with her. On Saturday she called me to ask when we were going out again! I told her - soon. A big change I saw in Nancy that night and what a wonderful change it was.

February 1988 –Cindy Herschleb

Important relationships set the context for change. Other people who deeply respect one's choices provide the reason to act.

Speak Up, Man

Tom's New Year's resolution was to use his voice. New Year's resolutions tend to be only as significant as their owners want them to be and I cannot speak for Tom but it is the timing of this decision to speak in which I find significance.

When Tom left [the rehabilitation program] after his motorcycle accident and began receiving services from Options he had benefit of a large assortment of service people to assist him in his transition back into his community. Among those was a speech therapist as well as a communication aids and systems specialist reputed to be renowned throughout the country. Over the two years I've known Tom I have attended numerous meetings in which providers of services assessed Tom's abilities as well as his motivation. The speech therapists used percentages to track Tom's progress. The information at staffings varied very little. "During sessions with me Tom is voicing 30% of the time. His motivation to voice is not consistent." Usually this was followed by a giggle and an, "You know Tom only does something when he wants to do it."

The communication aids and systems specialist assessed Tom and developed a program in which Tom used a computerized voice box to communicate. Tom did not like this system for two reasons. He said people were more interested in how the computer worked than in what he was saying and they looked at the computer instead of his face. He used to tell providers these things every time we had a meeting to assess his progress. They would ask him why he wasn't using his computer and he would tell them. They would reply that the novelty of the voice box was only temporary, that people would get used to him using it after a while. They would suggest that he use it for telephone conversations. They would promise him more variety of tasks at work if he used the box. They would tell him people in the work environment did not have the time or the patience to stop and wait while he whispered words very slowly. They would say the voice computer would help him meet more people, get more connected with his coworkers.

Tom saw it differently. He found people did take the time to watch his face carefully while he whispered words slowly pausing periodically for air or to swallow. He found he could communicate not only the words but his feelings about them with his eyes and with his entire face. He was never angry when someone did not understand what he was saying and he would repeat a word or a sound as often as it took to get it understood. It was clear Tom wanted people to look at him.

After a while Tom stopped talking at the staffings. Someone would ask, "Tom, are you using your computer at all?" And Tom would just sit there. And all of us seated with our notepads in our laps would look at Tom and wait. Finally a provider would answer for Tom. "He's not using it at work at all."

"Why aren't you using it, Tom?"

No answer.

And so it would go with all of us asking questions he'd already answered until everything was inevitably chalked up to his lack of motivation which was recorded and charted and documented on those note tablets in our laps.

Finally, MA caught up with all this lack of progress. The communication aids and systems specialist could not justify any more time working with Tom. She had a long waiting list of people needing services and she felt she'd done all she could. The speech therapist had seen no significant change in Tom's progress and therefore she could not get MA to pay for active treatment any longer. September was the last month Tom had anyone assessing his communication, of a professional nature that is.

So why all of a sudden did Tom find those muscles that help produce sound and what motivated him to put his whole body into emitting sound when he spoke? Only Tom knows for sure but I have some guesses.

One afternoon we were sitting at his kitchen table, Tom and Edwina and I, and we were talking about how those staffings feel. Edwina said she felt very uncomfortable, as if everyone was talking down to Tom. I asked Tom to imagine a staffing concerning my smoking habits. Playing the role of a therapist I started talking in a patient gentle voice. "Now, Kathy, we know it is hard to stop smoking. But your lungs are getting blacker and blacker and your refusal to do anything about it is only hurting yourself." Tom started laughing. And sometimes when Tom starts to laugh he can't stop. He laughed uncontrollably for a minute or so. And then he said, "It's nice when someone understands."

I think Tom decided to work on developing his voice because when he and Edwina have friends over for dinner he can't get a word in if he doesn't speak up. I think when he goes to the bank or the grocery store or out to a party he gets better results with the people he talks to if his words have sound. I think he does not feel the need to have someone stop and stare carefully at his face as much as he used to. And I think Tom is taking some control that he allowed others to grapple with in the past. Whatever the reason, all that really matters is that Tom saw the need to use his voice and so he decided to use it.

February 1990 –Kathy Lemke

When important relationships are deeply conflicted or exploitative, change takes courage, energy, and time.

"I Think I Finally Made It."

It was two years ago that I first met Olga. I remember with clarity how sad and overwhelmed I felt about how miserable her life was then. She had just quit her job a couple of weeks prior to our first meeting. I later discovered that she owed back rent, over $250 to Wisconsin Bell and was behind in utility payments, too. Soon her phone was disconnected and MG&E was threatening to do the same. She didn't have any money to buy food and was extremely worried about the fate of her boy friend, John, who was facing an upcoming court date on shoplifting charges. She had no benefits and no vocational provider to help her find a new job. In the weeks that followed, Olga related stories about how her neighbors at [a subsidized housing complex] had blackmailed her for sex and money and about being raped several times. It seemed to me that things couldn't get any worse for her. Then, Olga's father, whom she says acts like the "King of the Universe" began pressuring her to get out of this mess and move back to [the private institution where she used to live]. Olga, however, stood steadfast in her desire to remain independent in Madison. I often questioned whether this really was the best choice for Olga, but slowly things finally began to change for her.

Today Olga is celebrating one year of working in housekeeping at a large Madison hotel. She had to wait a while to find the perfect job, but Olga says it was well worth the wait. It hasn't been an easy job though. Olga almost quit a couple times and was suspended without pay a couple more. Luckily she has a boss who has also become a friend and who was willing to ride out those hard times with her. Tonight the two of them are going out for dinner to celebrate.

Olga is looking forward to getting a Section 8 rent subsidy soon. When she started her job she was able to escape the perils of the congregated, yet subsidized, complex for a small, but affordable, east side efficiency. Once out of subsidized housing, she was able to apply for Section 8 and is looking forward to getting a larger apartment when she's accepted into the program. After a long wait and a lengthy appeal, Olga was finally able to get SSI. With her medical benefits she was able to obtain counseling with someone she trusted. Olga hasn't come close to resolving all of her issues and is still vulnerable to being victimized, but she has grown stronger and can at least identify the kinds of situations in which it occurs.

Olga's relationship with her father still hasn't improved much. He still resents her decision to stay in Madison, but at least he's stopped his attempts to make her leave. He still thinks he's the king of Olga's universe but at least she realizes now that she doesn't always have to be his subject.

Really, the most significant change in Olga's life is the absence of John, her long time boyfriend and some-time fiance. When I first met Olga, she and John were inseparable. Their apartments at [the subsidized housing complex] were only a few yards apart, and they spent nearly all of their free time together. For years, many people in her life had been trying to convince Olga that John was using her and that the relationship was only contributing to the desperate situation she faced. Olga, however, was convinced that she couldn't live without him. She was finally able to learn otherwise, however, when John went to jail and Olga was forced to fend for herself. At first it was very difficult, because Olga had depended on John in many ways. He shopped and cooked and kept her organized as much as possible. Many times, Olga nearly succumbed to her father's pressure to return to the safety and certainty of [the private institution where she used to live]. Olga finally has a new man in her life now, a co-worker at the hotel who treats her with respect and she's starting to talk again about getting married.

Olga is celebrating another milestone next week. She has her back bills finally paid off and Wisconsin Bell will be resuming her service. I've never seen Olga so happy. "You see," she said to me recently, "I knew I could be independent. I think I finally made it." Yeah, Olga I think you wrote the book on it.

May 1988 –Julie Nichols-Younes

People use new opportunities to unfold themselves.

The Art of Freedom

"To know how to free oneself is nothing; the arduous thing is to know what to do with one's freedom."
–Andre Gide

Ken was freed physically four years ago, freed from a world in which:

"Kenneth continues to be a loner. On the ward setting, he will generally engage in considerable aimless pacing, and at times when he is pacing, he will laugh inappropriately to himself"

"...we will encourage socialization on his part with peers, although the prognosis for this appears guarded, as he has a strong tendency toward being a loner."

"...he can be observed to sit and smile or talk to himself, at which times he appears to be fantasizing or hallucinating."

"..he does not quite understand the abstract concept of defense in such activities as football..."

BEST COPY AVAILABLE

This freedom for Ken was easy. All it took was a CIP* plan, money, a station wagon in which to pack 25 years of possessions, and assurance that we would take care of Ken.

What has occurred since Ken was released has been an amazing unfolding and transformation. In some ways I think of this transformation as Ken finding out what to do with his freedom. It is Ken coming out, growing.

I think of it like a tree in a forest, a tree that is trapped by larger trees. It cannot grow because the larger trees stand in the way. Four years ago the larger trees were cut down, removed. Now the tree can grow.

For someone who rarely talked, whose prognosis for socialization was guarded, Ken has changed considerably. It is not uncommon now to sit down with Ken and talk to him for long periods of time. Ken talks about what he's been doing, what his plans are, life at [the institution]. Ken is constantly telling us now what he wants, how to do things, what he'd like to see happen.

Ken is discovering his power, his control... probably for the first time in his life considering he was institutionalized at a time in life when most of us are quite unsure about who we are, what we can do. And with the coming out is much uncertainty. Each time that Ken opens himself comes the possibility of rejection, control over him, failure in the eyes of others. Yet, Ken continues to unfold.

As the tree grows in the forest, the surroundings change. As the roots grow the earth is moved, plants and soil are disrupted. Growth is at many levels, beyond what we can see.

Ken's freedom also has unfolded in many ways. In addition to Ken's choices and relationships to others, he has, like the roots disrupting the soil, physically changed his surroundings by literally breaking down the doors and windows in his house. A struggle for me has been to fully understand these actions. Typically it is unacceptable in our society to intentionally break things, even if those things are yours. However, it also seems that Ken's life experiences have been much, much different than those around him, those who hold these expectations.

I feel that Ken is struggling with exactly what to do with his freedom. Sometimes he chooses to break things. Ken will probably stop this as he continues to figure out and explore the power of freedom. Until then, each sliver of glass from a broken window carries with it the energy from Ken's past. It is a physical representation of his many years of being controlled.

As I've come to understand what is happening in Ken's life I feel more comfortable talking to him about his "new life" and reflecting back on his life at [the institution]. I can tell by what Ken says that he understands the difference.

1987 –Sid Nichols

*CIP (the Community Integration Program) is an individualized funding source based on a medicaid waiver.

Giving People the Space To Be Who They Are

This is my last written story for a while, although I'm sure it will not be the last story I tell. My decision to not work full time after we have the baby was one of the hardest I've made. In examining why, it was hard to come up with one reason, but seemed to be more connected to what Options is and has meant to me over the past three plus years. Options has become the people whom I've come to know quite well, and isn't so much a job, as a way of life. It's been more of giving people the space they need to be who they are, than "doing" anything in particular for them. I'm sure I can't take much, if any, credit for the changes I've seen but it's been fun to think back to where people were when I started, where they are now and all the things I've learned.

I'm sure I'll never forget meeting Alice at East Towne shortly after starting at Options. She looked dirty and smelled worse as she tried to con me into buying her lunch, or at the very least, giving her $1.00. Her foster sponsor told me that Alice didn't like to wash or keep herself up, but now she yells

at me for her lack of money; she needs more to buy clothes - she can't go around in these rags much longer, you know. I've also seen her become less self-centered as she brings me little trinkets and treasures often and asks me every day how "too-toos" is in my stomach.

I've seen Don and Doug's self-confidence and self-esteem grow as they left [the work activities center] and started doing real jobs for real pay. No one has had to remind Don to wash or change his clothes since he's started at Wendy's. How long was that an unachieved service plan objective before he started working in the community?

I remember David reminding me continually about what a good social worker Christine had been and how much she liked him and wondering if he'd ever feel that I thought he was OK, too. And just the other day as I was walking down the steps from his apartment hearing him yell after me, "You know, you shouldn't want to get rid of me. I'm one of the best clients you'll ever have." And knowing that that's David's way of saying he thinks I've been OK....

There are lots of other stories, but all of them have taught me how lucky I've been to have people let me into their lives and teach me things about life and human spirit that I don't think I could learn anywhere else. I will miss not being involved in the day-to-day events of people's lives, but know that I'm going away with much more than I came with. I hope I never lose it.

April 1988 –Sarah Salzwedel

The importance of policy commitment to giving people the space to be and become themselves becomes sadly clear in this reflection on a situation in which a person had access to good training but not to the chance to become part of community.

I Wonder If She Wonders

I met Sherry six years ago. She was one of the first people I knew who was labeled "severe and profound", not only "severely and profoundly retarded" but also "profoundly deaf and blind". I was a student teacher then and my assignment was to teach Sherry how to clean a hotel room at the Howard Johnson's downtown. Sherry lived at [the institution] but she went to a high school on the west side of Madison.

I spent my first week getting to know Sherry. I followed her around the school and talked to people who knew her. I heard the story about how Sherry put her head through a plate glass window one day when she was angry. I heard about the temper tantrums Sherry threw when she didn't want to do something. But I didn't see that happen. I saw Sherry get off the school bus and feel her way down the hall to the one locker out of hundreds that she somehow knew was hers. She struggled to fit her key into the lock and open it up. I watched her take off her coat, hang it up, lock her locker and head for her classroom.

She certainly seemed to know her way around I thought. At lunch time I sat with Sherry. I would sign into her hand what they were having that day and then direct her hands to each part of her tray to show her where the different foods were. Sherry took it from there.

Sherry was a big woman, powerfully built and had a reputation of being periodically violent. Some people who knew her were a little wary because of this, but most people really liked her. She usually wore a look of intense concentration on her face that was rarely replaced by a smile. Sherry didn't seek people out for conversation, if Sherry wanted to talk it was to ask a question. She would grab your hand and take you to where the thing was that, for her, had no name. When you told her what the sign was she would do it a couple times and then she was satisfied. If it was something she wanted to know she rarely had to ask about it twice.

By that time I had started to wonder about Sherry. It was pretty obvious that she saw and heard nothing, but she learned things much faster than the other people I knew who also were labeled "severe and profound". I was excited about the chance to do vocational training with her.

The next week we started at Howard Johnson's. The first thing Sherry needed to learn was dusting and replacing missing or dirty cups and ashtrays. That day we spent time just giving things names. When I couldn't find a sign for something in the sign language book I made one up. Sherry worked hard and after a couple weeks it was obvious that she knew what she was to do on Monday and Wednesday mornings. I frequently wondered on how to explain things like replacing a matchbook with only one match missing, but Sherry's fingers were her eyes and she could see the missing match as well as I so that soon she was checking every matchbook.

After about eight weeks Sherry finished dusting two rooms quickly enough to start learning how to make the beds. This was a lot harder than the dusting for two reasons - one was that things needed to be very straight and neat which was difficult to do by feel and the other was that Sherry had obviously been taught how to make a bed before and she didn't want to do it *my* way, she wanted to do it *hers*. I saw Sherry's temper a couple times while we worked on this but she always got herself under control when I asked her to stop.

Well, Sherry was still working on the beds when my semester of teaching came to an end. I felt really optimistic about the future for her because of the determination she showed in learning about the world and being a part of it. I had also heard from the teachers that Sherry was being considered for community placement and would probably be leaving [the institution] soon. Everyone felt this was a great point in Sherry's life for this to happen.

I hadn't seen or heard of Sherry since then but I ran into one of the teachers who knew her a few months ago. We were talking about another student when I was reminded of Sherry and asked if she had ever heard how things worked out for her.

"Yes," she said, "actually I do know what's happening with Sherry these days. I was out at [the institution] a while ago and she's still there. I tried to talk to her but she didn't really communicate with me. She just picked out a sign that I made and kept repeating it over and over. I guess her home county refused to serve her and so she's never left [the institution]. She's not in school anymore so she really doesn't have anything to do."

Since that day it has been hard for me to stop thinking about Sherry. I am surprised at how sad and angry I feel knowing she sits in an institution with nothing to do from day to day. It is hard for me, living in Dane county, working in Madison, to imagine a county where Sherry would be impossible to serve.

I wonder if Sherry ever thinks back to her days in school. I wonder if she remembers the work we did at Howard Johnson's. I wonder if she wonders what that was all about and why I got so excited when she remembered to replace a matchbook or found a dirty ashtray under a chair.

March 1988 —Amy Lutzke

Dreams

Dreams stir and align people's energies and make effort worthwhile. Many people with disabilities have lived so long in impersonal and controlling environments that they have lost their willingness to share their dreams. When this happens their dreams become too small or too disconnected to shape their actions and recruit others to their aid. Some people may have even been so oppressed that they have apparently lost their ability to dream and act on their dreams.

Expressing a dream for another person focuses one's good wishes for that person, distills what one knows about that person, and opens one's sense of direction with that person for discussion and action. Dreams are not prescriptions or blueprints but invitations and guides. This expression of a dream for someone else must be clearly but loosely held with sensitive openness to the other person's responses. Otherwise it is not a good wish but an expectation whose frustration will lead to disappointment instead of to deeper recognition of the other person's uniqueness.

Simple images –almost fragments– of a dream for another person can capture a possibility that becomes real even when it seems unrealistic or a poor fit with a person's current preferences when it is expressed.

The Best Strawberry I Ever Ate

It's Monday morning. I pick Jeff up and we're off to buy new clothes.

"What did you and Carolyn do this weekend?" I asked.

"We had a cookout with some friends. We wanted to break in our new grill."

"What friends did you invite, Tom and Danny?"

"No, a friend of mine from work and her husband, and some friends of ours that just got married two weeks ago. They live in the neighborhood."

"What did you make on the grill?"

"Well, Carolyn and I bought the brats, two different kinds of pop, Koolaid, and I made a cake. Our friends brought potato salad and a great big bowl full of melon and strawberries. We had fun. We sat in the back yard and listened to music, and talked and laughed, and ate."

As Jeff was telling me this it reminded me of the first story I wrote. We were to choose a person and realistically write what we would dream for them. My story was about Jeff and Carolyn socializing with other non-disabled couples. After I wrote it I didn't feel it was very realistic so I threw it away. I didn't think it would ever feel this good to be wrong.

"You know," Jeff said, "Carolyn told everyone that I would never eat those strawberries. But I did eat one. I don't know why, but it was the best strawberry I ever ate."

July 1989 –Diane Steele

A dream can take shape when the dreamer looks back from a future point and describes specific good things as if they had already happened. Including another of the person's allies within the dream often strengthens the dreamer's voice.

August,1993 (5 years from the time of writing)

Dear Dennis,

It has been a long time since I have seen you. I had been thinking of you recently since it is the 5 year anniversary of my moving to Madison so I decided to write to you. I bet you are wondering how it is that I am writing this letter. Well shortly after I moved to Madison I had the opportunity to start working on some computers at the Waisman Center. For a while I just played games but I

also started to be able to read some words. A couple of years ago I met a man named Bob who I guess is a computer whiz. He figured out a way to program a keyboard for me using some words and some symbols like my communication board. Now when I type on this keyboard it prints out the words like this letter. I still get some help but it has been interesting learning how to use it. I can take the keyboard off the computer and carry it with me. It also has a voice synthesizer in it so I can use it to talk directly to people.

You can see that I have been busy. I am still working in the governor's office and am certainly pleased to be working for a democrat these days, although I did take a trip to the Thompson family home this spring. Tommy and I have become friends - he helped raise the money for me to buy my home computer.

I am still living in the house on Rutledge Street where you last visited me 3 years ago. Peter, Jodi and Bruce live here too and I finally let Jodi get a cat. I guess it's a pretty nice cat but I'm still not interested in having a dog around. I have met a lot of people in this neighborhood but I guess the ones most important to me would have to be Susan, Gary and their two kids David and Beth. They have made me a member of their family and are a source of joy to me. We spend holidays together and have gone on a vacation together too. David is 12 and Beth is 8. They seemed a little afraid of me at first (as I was of them) but we have gotten to know each other well. They have a pool and we have a good time there in the summers. The nice thing is that they just live 2 blocks away and so it is easy for me to visit them and them to visit me.

Oh yes, I still see Darwin who is also doing fine. We went together on a canoeing trip last summer and we had a great time. He keeps pestering me to go on some dogsledding trip they have in winter but I'm really not interested in having to spend my vacation with a bunch of dogs. Sometimes Darwin and I just stop and look at each other when we are spending time together. I know we are both thinking the same thing, "Did you ever imagine 10 years ago that your life could be like this?"

Do you remember Dennis when I moved to Madison 5 years ago and you were so angry because that aide had told me I would die when I moved here? Well, sometimes I think I did die, at least my former life did and then I was reborn into a new life. I guess I just want to say thanks for helping me get started in this new life, and I hope that more of the people I lived with get a chance to have a new life too. Well I guess that's all I wanted to tell you for now. Please come to Madison some time soon, I would love to see you again.

Your friend,

Terry

August 1988

–Amy Lutzke

Dreams for another person can arise from a sense of identification with a person's history. If that person has suffered oppression, the dream may be energized by anger.

Dreams

I would have gone to college if my life was different. I would have studied Black History, and about different cultures. If I'm going to understand other people, I have to understand their culture.

You know, I am fucking tired of all of this. I'm tired of people talking about love and kindness, but not showing any. There isn't anybody who walks through my door who really cares about me, or knows me. There is nobody who wants to exchange gifts with me.

How can you feel good about yourself if nobody tells you or shows you that you have any worth? How are you supposed to know? What do people want from me?

I want to write letters to the MLK people. I want to ask them what they are doing to reach the dream. It's nice to celebrate and have a birthday party, but what are they really working toward?

I'm willing to meet people half way, to accept what they tell me, but only if they are willing to accept me –to try to understand who I am. I have been willing to speak for a long time, but nobody has been willing to listen.

It hurts me deep inside.

January 1990 –Kim Turner

A Story In Two Parts

This is a story in two parts, or perhaps it is a trilogy to be. The first part was written at Options' Planning Day. Part One is the dream. Part Two is the reality.

Part One

P.C. joins the King Coalition to help plan for Madison's next MLK Day celebration. He helps the group focus on the idea that MLK's dream is not going to be reached by a once a year event. He shares his own story of struggle and isolation brought about by being labeled, and helps the predominately white middleclass group see their limited ability to truly understand the experiences he has had.

He speaks to a large crowd at the following year's MLK gathering at the Civic Center. He begins to have regular contact with people he meets (more than once and for more than fifteen minutes, which statistically speaking equals a friendship). He is invited to live with a couple of people he meets in this way.

P.C. begins to feel some acceptance of who he is, and some recognition of his gifts to others. His friends help him write letters and have opportunities to speak with different groups.

Before long P.C. is regularly traveling across the country and helping groups of people to understand more about oppression and labeling.

Soon a strong grass roots movement begins which brings millions of united people to Washington D.C. They paint the White House purple to express their dissatisfaction with our leadership living and acting out of a "white house".

The President, sensing that something is afoot, agrees to end all federal regulation and to allow communities to keep their money to help each other as they need. He quietly retires to Panama, a small country he recently homesteaded.

Options, no longer dependent on government funds, but on community support, is free to do their work of making spaces for people to live their lives eventfully and meaningfully.

Part Two

On April 5th P.C. attended a MLK coalition meeting. My usual routine when I'm planning a meeting with P.C. is to call him a couple of times beforehand to remind him and encourage him to get ready to go out. I planned to do this, but before I made my first reminder call, P.C. called me to ask what time I was coming. I told him I would be there in about two hours and suggested he start getting ready. He said he was ready, and had been ready for some time.

When I got to his apartment, I expected the usual wait while he finished gathering his things to leave the apartment. Instead, he was standing outside waiting for me! Amazing.

P.C. had decided to bring some articles he has written and his bongo drums to the meeting. He asked about how the meeting would be run. We went to the urban league building and waited for Maureen to arrive. I quickly introduced P.C. and Maureen to each other and left for another meeting.

Maureen reported that the meeting went well. P.C. shared his articles and participated in the meeting. P.C. also told me that the meeting went well, and that he would like to stay involved. He said that he felt like he was understood, and that the group was working for positive changes in

Madison. For the first time I heard him say something positive about his future in Madison. He said that he felt good that he could say he was doing something to help make Madison a more accepting place to live.

For now the story ends here after Part Two, which only covers the predictions of the first paragraph of Part One. I know the story will continue. I hope P.C. remains a part of it.

Note: P.C. wants readers to know that he is not a label and that he can be quite fancy when he wants to be.

April 1990 –Kim Turner

Roberta

"I have a dream..." a phrase from Martin Luther King, Jr. so powerfully etched into the political portrait of the sixties. The awakening of America. A growing awareness of the gross lack of civil rights of Black Americans and others, and the injustices suffered by many. Those words and the potent message behind them have beckoned to us over time to engage ourselves and our society...our community to respond, to examine our racism, to examine all the ways we oppress others through our actions or inactions either consciously or unconsciously...and to grow and change.

Roberta had an opportunity last year at Options' Martin Luther King Day celebration to read excerpts from his speeches. It was an opportunity for Roberta to review her life. Where she's been...where she wanted to go...to dare to dream. Participating in the Martin Luther King, Jr. celebration touched Roberta deeply...and her emotional expression of hope, dreams, and self-respect left her audience stunned.

Early on, while residing at [a private institution], Roberta had a dream: to live in a community in which she would be accepted, nourished and challenged. Roberta has told many that that day arrived years ago when she connected with Options and was assisted in making her place in the community. Roberta has established herself into new neighborhoods, developed new places to spend time, and new friends. Each time Roberta has had a positive move she has come to believe more in herself and her power as a worthy person. She has also grown more intolerant of the "less than equal" status that is sometimes thrust upon her by the bureaucracy, community people, family, and especially her work place. Last year Roberta clearly expressed her greatest desire and most sought after dream. Roberta wanted to be freed from [the activity center]. "It's just another institution. I don't need to be in an institution. I live in my own apartment in the community, pay my bills, have friends. I am a good worker. Why can't I work in the community?"

Today, Roberta's dream came true. She started a new job... a real job at a small fabric store downtown –Material World.

Today, Roberta has taken another giant stride to her own freedom. Never again will she have to return to [the activity center].

I had a dream... Roberta turned toward the [activity center] building with a huge grin and waved from the street shouting "Good bye [activity center...]. I've got a job."

"Free at last! Free at last! Thank God almighty...free at last."

January 1988 -LeslieWilmot

Even when people have worked together to make unbelievable changes and achieved a strong relationship, a person's dream may remain a mystery. It's important to remember and respect what is unknown about another person.

Some Unanswered Questions

Darwin and I rode the Metro Plus bus together last Tuesday to see a video tape at the technical college. Watching Darwin from across the bus, I wonder and I try to imagine what he's dreaming of. His face shows little emotion just now. How does Darwin pick his dreams? What's on his current list? How can he tell us? What is the "stuff that dreams are made of"? Dreams are sometimes things that we have little control over –they just seem to happen. Others, we work and strive to get, sometimes without success.

Darwin has been very successful at having his dreams become reality. And he's had some incredible dreams...

...to live in his own home, not a large institution; to eat what ***he*** wants for lunch, not what's been prepared for 100; to drink ***when*** he wants, not at staff's convenience; to have a paying job at the state, not sit alone and wad up newspapers; to go to the denomination of church he wants, not the only one that's provided; to get his hair cut when he wants to –not just when the barber is scheduled for his ward; to get a new wheelchair –or at least live someplace where they'd let him use the one he had; to go camping; to ride a horse; to go skiing; to fly in an airplane; to be on the TV screen, instead of just watching it...

Yes, Darwin has had some incredible dreams...

Darwin was one of the people filmed on the televised video we went to see. It was also shown at other sites across the country. It was an exciting event for those who know Darwin. As the film began, Darwin was very quiet. I heard some noise that sounded like laughter, so I turned around to smile at Darwin. But he was crying. What was he feeling? Was it happiness...pride...disbelief? Why wasn't he smiling and laughing?

Darwin doesn't have the words to tell us how he feels. And he can't tell us his latest dreams. Our communication is limited to Darwin pointing to baseball, swimming, or bowling –concrete pictures on his board that we can understand. Dreams and emotions aren't such tangible things.

So why was Darwin crying? Perhaps it was just the realization that yet another incredible dream had come true.

February 1988 **– Alice Sosinsky**

As connections deepen and people grow away from their life in oppressive places, more and more dreams will come from themselves. A person unaccustomed to sharing a dream needs a careful listener. A person whose dream calls for a change in his relationship with an important helper, needs respectful validation and the listener's willingness to figure out a changing relationship.

Pat's Goal

Last week I took Pat to a dentist appointment. As is always the case Pat talked almost nonstop. Pat's very honest when it comes to telling me how he feels. The only problem is that it often takes me a very long time to understand what he really means.

On this particular day he was telling me about his goals. He had talked to his vocational case manager that day and was feeling like he ought to tell me what he was thinking.

A few months back he had told me he didn't like his paid roommate looking through his shoulder and hoped that someday he could live alone and be his own boss like his brother and sister. After months of finding ways to give him more control, Pat decided this would be the opportunity to

bring this up again.

He started out by telling me he wanted more money. This I understood –so do I. Then he told me he was sorry Reggie got angry and that he himself wasn't fair. He then went on to explain that if he lived alone this wouldn't happen. Finally after a half hour of piecing together the many things Pat was saying I understood. He didn't understand why he should have to pay someone to live with him. And if he didn't have to pay someone to spend weekends with him, wouldn't he have more money?

All of this made perfect sense to me but I couldn't really give him an explanation he was willing to accept. He realizes Spencer gets paid to help them learn how to take care of their apartment but his sister didn't do that. She just learned by doing it. Reggie gets paid to help them organize their weekends but he didn't need help with that before, so why now?

Pat asks me a lot of questions about why we do things the way we do. He understands that sometimes people with disabilities need extra help. He sees himself as a person who offers that help by volunteering at Special Olympics but certainly not as someone who needs the help.

Yesterday at Pat's staffing he announced to all that his only real goal was to live alone, meaning not with someone paid to be there. Thinking about it later Kathryn and I decided he probably wouldn't eat very good and his apartment would be a mess. But both of us agreed if suddenly we were in a similar situation we would probably choose this lifestyle over one in which nosy social workers tried to tell us what to do and why something else would be better.

February 1990 –Missy Fizzell

Dreams have power when they include and enlist others and when they redefine important relationships.

The Beaches of Waikiki

What began as a savings venture much more than a year ago, ended as a vacation adventure for David in November. With a new part-time job at the Barrymore that began about two years ago, David and his father started talking about taking a vacation to Hawaii together. It would be a good trip for them, and a chance for his Dad to show David some places he had seen when he lived there before. The additional paychecks could make David's dream a reality.

And so David saved money for a vacation that probably seemed very far away. None the less his enthusiasm was high, and over the months his account grew. Although they weren't leaving until November, David was talking about plane tickets, bed and breakfast places, sites he wanted to see and other details almost every time I saw him.

At last October came, and the tickets were purchased. When I asked if I could help with some travel plans, David said, "No, my Dad and I are taking care of it." And they did. We looked at some books, David pointed out some places they were going to see, and my enthusiasm grew as well, just seeing how excited David was about this trip.

Finally November came. Again, my assistance wasn't needed because David seemed ready. I saw him make some clothes purchases, get the final itinerary, and purchase traveler's checks. They were leaving on November 28th and would return December 13th from their winter escape.

Hawaii was great David said. The beaches were beautiful, and they saw the tropical sites many of us only see in books. They saw the "real" King Kamehameha statue –as opposed to a fake one I suppose– when they took a private road they weren't supposed to, and David has the picture to prove it. They stayed at some bed and breakfast inns with great coffee and food according to David. They sampled some strange food and fruits neither one of us could pronounce. They went to a real Hawaiian luau one night, visited a sugar cane plantation, climbed Diamondhead, and checked out some authentic Hawaiian tatoo shops.

The travelers weathered a rainy day by seeing a movie, and even made it through a bit of vacationer's bad luck –losing a camera and some purchases– in fine shape.

David returned with some souvenirs, a University of Hawaii football jersey (you know the short, mesh kind), some pictures and other things, but most of all with some great memories. Memories of a trip he'd waited and planned for, for quite some time. That trip was a dream realized by David, his savings, and his desire to do something he'd wanted to do for quite some time. It was a great success, and David is already talking about a return visit - maybe in five years. And who knows, maybe they'll do it again.

March 1990 –Theresa Fishler

Family

Family molds people's identities. Beliefs about who your family is and where you fit within it shape your sense of what you are like and where you belong whether you want to move closer to your family or further away from it. Three generations of prejudice against people with disabilities have shaped service programs that distort family relationships for people with severe disabilities. Within the lives of most of the people that Options supports, families faced the hard choice of making it in isolation or following professional advice and institutionalizing a member. Some families stayed in contact with their absent member; some families were separated forcibly by professionals who thought they knew best; some families drifted apart.

Some people come alive in new ways when they are with their family.

One of the Best Visits

It is Monday morning and, once again, I wonder if I'll be seeing Mary. We've had a set appointment for the last few months, but we rarely connect. At 10:30 I dial Mary's number to discover once again, she's not around.

This afternoon as I'm preparing to go out for an appointment Mary calls to say she has her bank statement and would I like to go out for coffee. We arrange a time for the following day and say good-bye.

Tuesday morning I drive to Mary's to find she's not home. Just as I'm leaving I see her coming from the bus stop. She explains she needed to go to Sentry, but is ready now.

After a short drive and very little conversation we arrive at Triggs. As we sit down with our coffee Mary hands me her bank statement and tells me I should do it now, so we can talk about other things. While I checked over the statement we chatted about work, finances and Mary's life in Madison. During most of the conversation, as is the case with many of my talks with Mary, she remained expressionless and distant.

We finished our coffee and I asked Mary if there was anything else she wanted to talk about. I had barely finished my sentence when Mary came alive. She beamed with excitement as she said she'd like to tell me about her trip to Rockford.

She told me of her mother's 75th birthday party, the phone calls from her children, and went over, in great detail, the dinners out at "spanky, extravagant restaurants". For thirty minutes Mary talked non-stop of "one of the best visits she's ever had".

As Mary's story came to an end the excitement I had seen in her eyes minutes before was gone. The pictures of Rockford I had in my mind were fading, and so was Mary's smile.

Our visit came to an abrupt end when Mary had a seizure, which is reticent of Mary's life. She was taken from her family, her children and her home to be put in a hospital and eventually a nursing home. Finally she was given a new home to start her life again.

I asked Mary if she ever thought about wanting to be closer to her family, to which she replied, "I'm happy here. I have friends, a job and I'm doing OK." Somehow it's not as easy for me to see Mary's life here as being happy compared to her visits in Rockford.

Are you happy here, Mary? Where is the feeling and excitement you share with me in your stories about home? I wonder what your life would have been if there had been an Options in Rockford when you needed it most.

June 1988

–Missy Fizzell

Other People

Dorothy is to return on flight 258 from St. Louis. She is returning from a visit with her daughter, Diane, in Texas. On the way to the airport I think to myself, "Dorothy's not going to be on this plane." Sure enough, as I stand watching people streaming off the plane, greeting family and friends, Dorothy is not to be found.

So the search begins. After many phone calls, I discover Dorothy is sitting in the "unaccompanied minors lounge" in St. Louis, having lunch. I call her daughter, Diane, to share the news and give her the phone number of the lounge so she can talk with her mom. Diane begins on the phone, telling me, an unknown person, stories of her life, her mom. Initially, I resist this push into her private life and into Dorothy's. But I listen to Diane's tearful voice, miles away, in a southern drawl:

"My dad was always real good to my mom. He brought her home to the house on weekends. Usually one weekend a month so she could spend time with the kids. Then my dad got remarried. Sometimes I wish I lived up there. My older sister, Donna, lives only three miles from mom. She's afraid she'll end up like mom, so she doesn't see her much. But she's starting to do things with her, like take her to the movies or invite her over for Thanksgiving. She's coming around. I didn't know what to buy mom for Christmas. So I bought her a necklace with a little head on it that says "Trisha", the name of my four year old. I thought in the future I'd get her some more charms with the other grandchildren's names on them. My daughter liked having mom here. She'd go up to her and say, "Grandma, hold my dollies."

I imagine Dorothy in her new blue outfit she bought specially to see her daughter. I see Trisha putting "dollies" onto Dorothy's lap as she sits passively in a chair, slightly rocking. And I think of our conversations about family at Four Lakes Restaurant. The only time I see Dorothy animated and enthused is when talking about her children, especially her daughter in Texas. She is curious about my own family, asking me how far away my mom lives, and do I ever get to see her. I enjoy these rare conversations with Dorothy.

And although Dorothy had a long day travelling home to Madison, I was glad for the chance to learn a little more about her life. She arrived safely home at 4:58 p.m.

February 1988 **–Kathryn Mazack**

Knowing someone's family history yields new understanding of who they are.

Family

Mike and I sat in the kitchen of Tom's home - a house he has been slowly building for himself on a small piece of land in North Carolina. Tom poured us some coffee and brought out a pile of old family pictures.

"Here is a picture of your father, Mike, and here is your grandfather "pipi" and grandmother "mimi". That's how you say grandfather and grandmother in French."

I told Tom that Mike has often said that his is a French name. Tom told us that their grandparents came here from France around 1900. Tom continued to tell us about Mike's family. "Mike was born in Ontario, Canada in 1935. I was six years old then; my family had moved there onto a homestead 100 miles from anywhere to try to escape the depression. It turned out that it was even worse there. Our family - Mary, Lucille, and myself, then Mike lived in a small shack. The year Mike was born was very bad - we had almost no food. Mother had almost nothing to eat when she was pregnant with Mike except rutabagas. I think that Mike is the way he is because of malnutrition during mother's pregnancy and when he was a young child."

"Lucille has the same problem - she does OK though. She takes care of herself. Sid, too - he was OK I think. They took him away when he was a baby - he never had a chance to develop. Now he is a con."

The family eventually got enough money to return to Wisconsin. When Mike was three years old, right after Sid was born, his parents separated. His mom left, and his dad had a drinking problem. Mike and the kids went to live with an aunt and uncle till Mike's dad could get back on his feet.

"Dad got a housekeeper and we moved back in with him. We lived together for a short time. I remember this as being the only time the family was together and happy."

Not long after this Mike's father left to join the Merchant Marines and nobody heard from him for eight years. The kids were all split up - Tom to a boy's home for orphans, Lucille and Mary to a girl's home. Sid went to an infant's home. His aunt and uncle wanted to keep him, but the county took him anyway. Mike was sent to [an institution]. He was four years old.

The next time Tom saw Mike, Tom was fourteen and Mike was eight. Tom went to visit Mike and Sid (he was now at the institution too). "It was awful. They treated them like vegetables. There was a big room full of men. They had Mike in a room with men in cribs with diapers. He was just a kid. They didn't treat them like they were human. They seemed to think they had no feelings like other people." The rest of the family - aunts, uncles, etc., thought Tom was crazy to try to see Mike and Sid. "I tried to get them out, but I couldn't. I was too young."

Tom left Wisconsin and joined the Marine Corps when he was seventeen. "I got out as soon as I could. I couldn't stand it." Tom stayed in the Marine's for twenty two years. He tried to stay in touch with his family.

His father came back and was eventually remarried - to the woman who had been his housekeeper before. He sobered up, and stayed sober until his wife's death a few years later. "My Dad was a genius and a drunk. He made Captain in the Merchant Marine's in four years. He spoke at least eight languages. He never saw Mike after he left when Mike was four years old. He died when he was fifty two - Mike's age now, of alcoholism, alone and broke in the California desert. I managed to see Mike about once every five or six years. When he got older they kept him doped up. He was incoherent." Eventually, Tom did manage to get both Mike and Sid out of [the institution]. "I wanted to try to keep us all together and to give Mike and Sid a chance at a better life."

He drove both Mike and Sid from [the institution] to his home in North Carolina, where he settled when he got out of the Marine's. "I fixed it up as nice as I could - they both had their own bedrooms."

It didn't work out - Sid didn't like it in North Carolina - he got sick and wanted to go back to Wisconsin. Tom and Mike drove Sid back to Milwaukee. Mike and Tom returned to North Carolina for a few months, but eventually Tom decided that it wasn't working out for Mike either. He was not familiar with the surroundings, or his new life. He got homesick, and Tom brought Mike back to Wisconsin, too. Milwaukee County placed both Sid and Mike in a nursing home - _____view.

Tom has kept in touch with Mike, Sid and Lucille. He lost contact with his mom and his sister, Mary, but he heard from some other relatives that Mary has eight kids and lives in Wisconsin. Sid lives in Racine in an apartment now.

Tom learned fours years ago that they have eight half brothers and sisters. One of his half sisters had been adopted as an infant and was tracking down her birth family. She had learned about Tom and contacted him. Their mother had died the year before - she was about eighty years old. Her last child was born when she was fifty two years old. There were three sets of twins and two other kids all adopted by families in the Chicago area.

Tom felt badly that he was not able to reunite his brothers and sisters. I tried to reassure him. I told him how important family was to Mike, and that the only way Mike ever had a chance to experience it was through Tom's caring and love.

"I do care about Mike - he's my brother."

February 1988 –Kim Turner

Some people need practical assistance to maintain family ties and to take their place at important family events as well as help to make sense of family transitions.

Blue, White and Awful Pretty

The sky cried out rain as I made my way to Portage on an overcast autumn-like day. I felt strange as I was on my way to a funeral for a person whom I've never met before. But I knew this person's son - Alan. Alan's father died September 17th of a heart attack at age 68. Just to be there for Alan - that was all I could do, I thought to myself. Alan welcomed this "support" - as he called it.

At the funeral parlor Alan introduced me to his family - his three sisters and his brother-in-law, Charlie, whom Alan felt close to and occasionally talked about. And lastly, Alan led me to his mother who sat in a wheelchair near her husband. She managed to smile and reach out her hand. She inquired about Options and my role in Alan's life. I briefly mentioned I help Alan manage his home, assist him in writing out a menu and grocery list weekly and help him pay his bills. She asked me if Alan eats his vegetables. I assured her he does. (Sometimes.) She's a sweet lady and I can see Alan in her, I thought to myself...

The service was short and simple yet very meaningful to the people Alan's father left behind. The minister's words had a familiar ring yet were comforting. As the minister put it, "This service isn't for Bud (as he was called), but for his family and friends." He felt it was a way for them to deal with the grief and anger that often accompanies the death of a loved one. A way to accept it and move on. He mentioned that many people wonder why. "Why did God take Bud from us?" He thought that we ought not to ask God that but to thank God that Bud was here. "As many of you", he said, "wouldn't be here today if it weren't for Bud." He also asked people, on a closing note, to share stories about Bud with each other, not only as a way of grieving but also as a way of remembering him. Later I asked Alan if he had any stories to share and he nodded yes.

Throughout the funeral and over the past few weeks Alan has thought about death and dying in sad, yet in healthy and peaceful ways. He has struggled with many questions and concerns. "What will happen to my mom now? She can't get down the stairs, or uptown or manage the house by herself. What will happen to me when I die? Where is my dad now?" The last question, "Where is my dad now?" Alan has given a great deal of thought. While over at Alan's house the other day, he asked me where I thought his dad was. I mentioned I couldn't answer that, but, I replied, "I feel your father is where you believe him to be." Alan, laying on his living room floor (as he sometimes does when he's thinking hard) sat up, nodded and told me about an experience he had. In short, it went something like this...

"I want to tell you something. I used to go to the Workshop and one day I was electrocuted - 220 volts went right through me. Right then I felt something touch me on the shoulder and for a time everything was blue, and white and awful pretty, awful pretty," he said with sincerity. Alan was silent. "Is that where you think your father is?" I asked. Alan paused and then with a very sad, yet peaceful, expression on his face, he nodded yes. "What do you think?" he asked. "I think so, too, Alan," I replied, "and it sounds like a very nice place to be."

October 1988 –Janet Morgan

Home for Christmas

For several years now John and I have headed out of town for the holidays together. It all started about four years ago when my team and I decided to help John visit his brother Elmer at his nursing home for Christmas.

John and Elmer had lived together at [a nursing home] here in Madison. For some unknown reason when [a local facility] closed Elmer was sent to a nursing home in Wisconsin's north woods, while John remained in Madison. Christine thought there was a VFW hotel that John had stayed at

on a previous visit so I began to help him make his plans. I volunteered to drop John off in Wautoma on my way home to Sheboygan since the bus trip wasn't something we thought John could negotiate without help.

That first trip was a story in itself. Just as John and I were leaving Madison at 4:30 in the afternoon it began to snow. The traffic was a little heavy going north but the roads weren't too slippery. The snow just kept falling. We got to _____ at about 6 p.m. It was dark and there was a good six inches of fresh snow beginning to drift in the now blowing winds. John and I found the VFW and got him checked into a turquoise room, 8 X 10, naked bulb from the ceiling...well, you get the picture, not exactly cheery. The bar downstairs was warm, decorated for the holidays and filled with the locals stopping by on their way home from work. John looked very at ease there.

We asked directions to the nursing home which was three blocks away and headed off bounding over the drifts, shielding our faces from the blowing snow.

The nursing home was bright and warm. The staff greeted us and seemed delighted that John was going to be around to spend several days with Elmer. We walked down the hall to Elmer's room. He ran to John and threw his arms around him the minute he saw us coming. The apprehension I felt about venturing out into the storm was tempered by the feeling of warmth that came from knowing that John and Elmer would have a good Christmas.

I was fortunate enough to follow a snowplow to Oshkosh and made my way to Fon du Lac OK. I knew that the worst part of the trip lay ahead, the dreaded highway 23, 35 miles of hills and curves through the heart of the Kettle Moraine.

As soon as I got out of Fon du Lac the road disappeared under a blanket of white. It took me only a moment to realize that one of my headlights had burned out on my way through town and as my windshield wipers began to ice up the amount of my windshield that I could see through dwindled to the size of a 3 X 5 recipe card. Pulling off the road to de-ice then was out of the question since I was never :eally sure I was even on the road.

Well, I'm here today so it's apparent I made it. I won't relate the tale of mine and Sarah's return trip to get John except to say that Sarah was thrilled to get a sweatshirt at Slife's Y-Go-By tavern where we waited for the tow truck, since Slife is her maiden name, and I was thrilled that Options paid for the tow to get us out of the ditch.

In the subsequent years I discovered that by taking John to the Greyhound depot in Beaver Dam he could catch the bus that would take him directly to _____. What a relief!

Last year John started getting official looking letters about a change in guardianship for Elmer. Their sister who lives in Milwaukee was appointed guardian and soon we heard that Elmer was moving to _____. I again agreed to give John a ride at holiday time since I drive right by there on my way to Sheboygan. Maureen struggled with finding a place for John to stay and communicating with new nursing home staff but finally managed to put together the arrangements.

I picked John up on Saturday morning and headed out. It was very cold but clear and sunny. We talked about the last trip and wondered what the new place would be like. We turned north and I saw the nursing home on our left as we drove toward the _____ Motel. I was concerned that there didn't seem to be any sidewalk for John to walk on but the road was wide and there was grass along the sides. Then abruptly as we crossed the County line the road narrowed to two lanes and we were in the country with only the ditch to the side of the road. On the right I saw the motel and I turned up the long drive to a small white house and a row of connected motel rooms.

We entered the lobby and a woman about John's age came up to the desk. I said John had a reservation which she confirmed and then gave me a card to be filled out with John's pertinent information. John asked me to write it for him so while I did that I asked if there was cab service in the area. "Well, there is but you have to call them out from the city and it will cost you at least $40," she said. "Now who's responsible for him?" I kind of hemmed and hawed and tried to look confused until she clarified, "If he has any trouble who can we call?"

"Oh, well, you can call me if there's a problem," and I wrote down my number in Sheboygan. I had to throw in a, "I wasn't sure what you were asking since John is responsible for himself."

We took his bags to his room and a nice room it was. It had a big bed, some chairs, a TV, a sparkling bathroom and a picture window view to the woods outside.

Next we headed to the nursing home. When we pulled in the drive I saw an elderly couple leaving the front entrance. John and I went up to the receptionist's desk. The lobby was empty except for a small woman about 40 who was staring at the elderly couple as they drove away and quietly crying.

The receptionist sent us around to the nurse's desk which was staffed by three women. I noticed a lot of people milling about most of whom were middle aged and seemed to have a disability. The staff seemed to remember some memo about John but couldn't remember what it said or who he should give the money for his meals to. One of them went to find the memo while I asked the other woman if there was anyone who drove by the motel on their way to work and could perhaps transport John. She said she didn't think so but she thought he could take a cab and they would help him with the arrangements.

Then we went to find Elmer. As we started down the hall I noticed a strong smell of urine permeating the air. There were a lot of people sitting around, the place quite frankly looked a lot like a state institution. We found Elmer's room and knocked on the open door. We walked in and saw Elmer laying in his bed, fully clothed and covered up facing the wall. When he heard John's voice he jumped out of bed and ran over to give John his big Elmer hug. I noticed the bright orange peeling paint on Elmer's side of the room wasn't covered by any pictures or decorations. Elmer's roommate sat in a rocking chair watching us, smiling and rocking.

Shortly after that I left. I felt bad heading to my family's home and leaving John and Elmer in that terrible place. I thought I should have had Elmer pack a bag and delivered them both to the motel. I could have found them the phone number for a pizza delivery place. Anything to get them out of there.

Instead we talked about it at our team meeting the next week. We decided it was time to try to find out why Elmer left Dane County and why he's in a nursing home. We decided to try to get Elmer out and bring him to Madison so he and John can be together in their place whenever they want.

January 1990 –Amy Lutzke

Family is too important for staff to assume that people must remain cut-off from their families if there is any desire to re-connect with them. Unless support staff are thoughtful about their role and active in reaching out, many people will remain isolated from their families.

A New Beginning

Jean turned sixty last weekend. She felt lucky that her 60th birthday was on Easter Sunday. Jean is a very religious person.

Jean has had a rough couple of months. It started off last December when she began to lose bowel control. Her thoughts were that she would need to return to a nursing home. (She had lived at [a nursing home] for 25 years.) In January her father died. While Jean didn't express much grief over his death, over the next two months Jean became very depressed. As a result of feeling depressed Jean was not sleeping well, was often confused and needed much more support in her life. It also was apparent that Jean needed people to talk to in order to process her father's death.

I have always known that Jean was an isolated person. She has family and a few friends, but due to the difficulty she faces getting around town, she seldom saw these people. During this time when Jean was frightened and confused it also seemed that myself and her attendants couldn't be the primary support for her. I have only known Jean two years, Beth has known Jean for a little over a year and her other attendants know Jean from their occasional weekend work. None of us knew

Jean's father. It also didn't make sense for Jean to process her feelings with her service providers seeing as she did have family and friends.

What has begun to happen as a result of all this is a re-commitment and drawing in of family and friends.

When Jean first began to feel confused and depressed I called her brother who lives in [another community]. He explained to me that in the past, when Jean has gotten depressed, the family referred to it as "one of her spells". He went on to talk about Jean's life in the past.

So often families have become so disconnected from a family member who was institutionalized. It appears that the family doesn't want to be involved. This was the case with Jean's brother. However one of the real causes of the disconnectedness is the service folks never ask for family involvement because the service folks know best.

I found Jean's brother informative and helpful. I also told him that it seemed Jean would need people to talk to about her father's death. Since that time Jean's brother and his family have been more involved with her life. They have been over to see her more often, they threw a surprise birthday party for her.

Jean's niece has also become more involved with her. Michelle does some attendant work for Jean. Beyond the attendant chores Michelle has spent time talking to Jean about her father's death. Michelle's father (Jean's brother) also died a couple years ago. Michelle and Jean have a common experience that they have begun to share. Both Michelle and Jean enjoy each other's company.

Jean has a friend, Betsy, who has known Jean for the last five or six years. Betsy gets together with Jean several times a month. Aside from doing things that friends typically do, Betsy also helps Jean with exercises and mobility. Betsy works as an OT so her relationship with Jean includes her knowledge of adaptations, etc. While I was out with knee surgery Betsy volunteered to be Jean's "case manager" with health problems, etc. This seemed to make lots of sense since she knew Jean better than anyone here.

Jean is also beginning to be re-connected with people she has known in her past. She really wants to talk to old friends who can share in stories and whom she trusts so that she can talk more about her father's death.

April 1988 –Sid Nichols

Jim's Christmas

The phone rang last night. Nancy said, "Kathy wants to talk to you." The thoughts raced through my mind... what now... a problem with Christine, or Jim is mad... this is the last thing I want to deal with.

But, it was great news... Jim's sister had called Kathy to tell her they wanted Jim home for Christmas. "'This is where he belongs, with family,' she told me," Kathy said. "This only a year after Jim's mom `washed their hands of Jim'." The wonderful thing is we didn't have to pressure his family to take him home... the power of family came through... even without a case manager.

Jim's voice echoed through the halls... "Hi, Mr. Sid. Go to home, see my sister Kathi, for Christmas tree." The smile sent happiness throughout. Jim felt family again.

I called to see how things went with Jim, home and Christmas. His sister was mad. "You guys never get the buses straight. I had to run all around. Why wasn't the bus on time... on and on." When I got around to asking how things went with Jim she said fine, that they had a nice time seeing Jim, that Jim really enjoyed himself. She said she hoped that *next time* we get the bus thing straightened out. She was still mad at us. But she did say *"next time"*.

Jim was waiting in the hallway when I came in the door. "Hi, Mr. Sid," with his wonderful smile.

He said he had a picture of Kristina, his niece who he saw at Christmas. He was excited because she is pregnant. Jim said she's having two babies. He said he had a fun Christmas at his sister's, he showed me his blue sweat shirt he got from his sister, Kathi. We talked a while longer about his hometown, weather and work. Jim got ready to leave and wished a "Happy New Year Mr. Sid."

–Sid Nichols

Involvement with the meaning of disability in other's families prepares for understanding of events in one's own family

Twists of Fate

A few months ago, a baby was born. This baby was the second child born into a happy, young family. It was to be such a joyous event, with grandparents and friends and aunts and uncles around to celebrate. However something different happened, something unexpected. The little boy's arrival brought concerned looks to the faces of those around him. He was carried to the other side of the birthing room, looked at closely, and then returned to his mother and father with an explanation - your baby has Down Syndrome.

Within five minutes of entering this world, the little boy was given a label, a diagnosis which was to change his entire future. The shock waves from that statement rippled out throughout his community as the news was shared with friends and family. Within moments, a baby became a "Down Syndrome Baby", a family became a case, and a childhood would become a series of assessments and closely scrutinized development.

It troubled me that upon hearing the news of the birth, I thought not of who he looks like, and other baby issues, but of what his future, his adulthood would entail. And I was troubled by my fear and my pain. My reactions caused me to think of other stories told around this table and of other people who have recently become part of my life.

I think of Charlie, who told us through Alice how he had to escape from [the state hospital] all the way to New York to create his own life. He asks that no twist of fate now take it from him.

I met a woman named Dorothy last week. I don't think I will ever forget. Dorothy made the mistake, it seems, of being in the wrong place at the wrong time. She was born in 1914. Three years later her mother died and she was moved to a "Children's Home" - just the first in a lifetime of unfortunate placements. Apparently, due to a disability of mental retardation Dorothy had, her brother was adopted out to a family and she was not. Or perhaps it was because he was a he, I can only guess. At any rate, Dorothy moved from Children's Home to Detention Center, to the Big House in Union Grove, to one Nursing Home and finally to another, with a few "attempts" at Group Home life beginning at age 65. Dorothy sits in her new home of two years telling me of her wishes to go outside and walk and plant flowers, and of her strong desire to return to her home of 40 some years to see her friends (this being the previous Nursing Home). I can't help but think if only her mother had lived ... if only she'd been born 70 years later ...

I think of Tom, who by being on his motorcycle at the wrong time and place endured years of institutionalization and perceptions of those caring for him of no other possible existence, before he found his new life in Madison.

And I think of Nancy, who went to a school as a youngster which seemed unable to take her in, beginning 25 years of institutions, group homes and many foster families.

And of countless others, and those twists of fate ...

The baby boy seems to be doing OK so far. I can only think that 1988 provided a more open, accepting world for all new babies. He's healthy, he will be living in his family's home. His family is

well connected in their community, and they have a positive outlook for his future. His school system is so ready for him he's already enrolled at age three months. But his misfortune came with having that extra chromosome and those infamous physical characteristics.

I cannot stop thinking about his future. I suppose this is influenced by the stories I know, the life I lead, and the work I do. Who will be his friends? What will be his interests and career? What will be the values and philosophies of those who help him create his life? And how will he work through the inevitable hurdles?

I feel a bond with this little guy as I fear for his struggles and hope for him a kinder community which will respect his personhood. While I'm concerned over how his perceived differences will complicate his life, I am overcome with amazement watching him grow, and I look forward to getting to know this new person, my little nephew, Charlie.

February 1989 –Maureen Quinlan

Friends

Friends offer companionship, support, assistance, and a sense of belonging to a wider community. Typical human service practices reinforce common prejudices and diminish severely disabled people's chances of making and keeping friends. Segregated away from the ordinary patterns of community life, congregated and transferred from place to place for staff convenience, and treated as if their relationships do not matter and their sexuality menaces society, many people with severe disabilities experience isolation and loneliness. This important fact of peoples' lives calls on Options' staff to learn how to respond actively and sensitively.

Time and Love and Work

A lot has been said and written about friends, and I think it's true that you can never have too many of them. Sometimes friendships become more like family and it makes us change our definition of what "family" means. In the last few weeks I've heard stories and attended gatherings which have overflowed with the warmth and color of real friendships.

Darwin, Glen, and Randy threw their annual October party to commemorate... let's see... Well, I guess it's the anniversary of Darwin moving out of the institution four years ago, moving into the Reservoir Co-op two years ago, and four years of the three of them being together. Not only do the relationships among Darwin, Glen, Randy, and the other support workers go beyond working relationships, but all the co-workers, neighbors, co-op members, friends, and friends of friends made for a true house warming. The house was buzzing when I got there and I even missed the peak of the crowd. I wonder if Darwin, who was clearly enjoying the celebration, ever imagined when he was at [the institution] hosting anything like this some day.

A few days later I went to another festive housewarming at Chris and Tim's. Again, a full house. Chris looked better than I've ever seen him, and their cozy home welcomed all. Don mingled with everyone, telling jokes. Most everyone there were strangers to me, but it was obvious they were friends of Chris and Tim.

More evidence of friendships happened over Thanksgiving weekend, when Jean accompanied Beth and Aletha to Beth's family's home near Sheboygan. Beth was once Jean's live-in attendant, and Aletha currently is. It is unusual that former workers stay in touch with people they supported. With Jean, not only has that happened, but Beth and Aletha are good friends too. I wasn't there, but I bet at *that* family gathering Jean and Aletha were considered family.

Last but not least, there's Christine. She is someone whose list of friends is heavy with social worker types, which should be no surprise considering the surroundings in which she's lived. A few months ago I began to hear mention of Dan and Theresa. Chris told me they lived across the street from her. Once she said they told her that if she ever had a problem or needed a place to stay, she was always welcome at their house.

They came to her birthday party at the Nitty Gritty with a nice gift, and Theresa came to court to support Chris about an incident involving Chris's upstairs neighbor. Theresa has advocated for Chris throughout this period. In a nutshell, Theresa and Dan are neighborly, friendly, and supportive. To them Chris is a neighbor. From across the street, they found each other with no help from anyone else.

Jean and Chris and Darwin and Glen and Christine have had varying opportunities to form real friendships. It hasn't always come easily. Those relationships don't come about through the efforts of us service providers. At least not very often. Real friendships happen naturally, and they grow when time and love and work are put into them.

December 1989 —Peter Bazur-Leidy

Casual neighborhood relationships offer pleasant moments and create the possibility of deeper relationships.

Wind, Bees and Flying Potato Salad

Rrrr, Rrrr. A fire truck screeching down the road catches Sandy's attention. She glares out her sixth floor window which faces Meriter Hospital and spots the scene below. "That's a fire truck from station 6. I wonder what happened. You know every time I hear that siren it breaks my heart."

"Your heart must have been broken a million times over," I said jokingly.

"Yeah, but my friends from the fire stations do a good job of mending it," replies Sandy.

"By the way," I ask, "have you seen any of your fire fighter friends lately?"

Sandy's face glows with excitement as she proclaims, "Captain Bigham made me breakfast at the fire station just the other day. He sure is a good cook."

"That he is," I add as my mind wanders and I think back on last summer's picnic with Sandy and her friends...

It was a hot summer day and the wind played havoc by making newspapers dance in the street, trees bend over and potato salad fly. Sandy and I met her friends at Brittingham Park for an afternoon picnic. Her friends from the fire stations were there, Captain Bigham, Lieut. Schnauzer, Bev Ward and a neighbor, Sue. We decided the shelter house may provide some relief from the blowing wind. We had no idea what to do with the bees that decided to join us. Sandy, in charge of setting up this picnic, had everyone bring something to eat or drink. She also designated Captain Bigham as the cook. We had the makings for a mighty fine picnic - hot dogs, hamburgers, potato salad, soda and beer but one thing was missing - a grill. I jumped to the rescue and went out in search of a grill. When I returned I was eagerly welcomed back by five hungry, wind blown, bee-d-out picnic goers. Cap, as Sandy calls him, went about cooking the hamburgers and hot dogs. The rest of us, including the bees, gathered around a picnic table near the shelter's one and only wall. We chatted, held down our drinks and occasionally chased picnic supplies which ran off with the wind. Then the moment we were all waiting for. "Come and get it," the Cap proclaims. Little did Lieut. Schnauzer know what he was getting as he sat down next to me and my plate heaping full of potato salad. My eyes and mouth went right for the sandwich on my plate. The next thing I knew my plate full of potato salad was in mid-air heading straight for Lieut. Schnauzer. It collided with the Schnauz's face. I was quite embarrassed as he peeled the plate off his face, but the Schnauz took it well and laughed with the rest of us. Sandy thought the picnic was a smashing $ucce$$, especially when she received a 5 spot from both the Cap and the Schnauz for putting on the picnic.

I felt something nudging me as I found myself back in Sandy's apartment. "Jan - are you there?" asked Sandy. "I thought maybe this summer we could have another picnic and the Cap could cook."

"Sounds good," I said. "I wonder if the Schnauz will come?"

July 1987 --Janet Morgan

Staff members who share their own relationships expand the social connections of the people they support.

Jim is Learning To Talk Better

Every Friday Jim and I would go to the Sun Prairie Bowling Alley to watch Diane and Geri (my sisters) on their league. Jim looked forward to Fridays to see his "buddies", as the team also to see him.

As time went on, Jim showed Diane and Geri a few signs they used every week. Like when Diane would miss her spare, she'd turn around and sign "Shit" while muttering it, and Jim would join in with her.

Geri would order a beer and sign to Jim "Good beer" and Jim would sign, "Bad" and then put on a silly drunk face and give a hiccup and point at Geri and crack up laughing - also signing "No... Geri, yes...".

My parents would come toward the middle of the game and sit with us and Jim would tell them about his two jobs, sweep the floor, mop the floor, bathrooms, windows at the Fish Store...

When Jim left to go to the bathroom, Dad leaned over and said, "You know, Kathy, Jim's learning how to talk better! I snickered and said, "No, he's not. You're starting to understand him better!"

To this day, they can make out 75% of what he's telling them without my help.

–Kathy Hart

Other people provide crucial supports when times are difficult. This support not only affects the person with a disability but those who assist as well.

Susan's Community

I hear the murmur of the TV news in the next room, discussing the day's highlights as I make dinner and try not to think about work. I concentrate on the carrots and broccoli as I chop, focusing my thoughts on the shapes and sizes. Again, my attempts fail, and my mind wanders through the feelings and events of recent weeks.

This post-holiday winter has proved to be an exhausting time. As I witnessed Susan take the big step to go off the neuroleptic med she was on, I celebrated, and as I've seen the pain, sadness, confusion and fear come in and take over her life, I felt despair. We helped her get into the hospital, attempted to maintain some sense of stability while in the hospital, and helped her to get out. As Susan and those who care about her struggle through these difficult times, I feel myself trying to take on the responsibility of these problems, and this life. As I work to ease the burden on Susan, the weight of this responsibility builds.

I do not know the experiences she's having. I don't know what it would be like to be afraid of your own home, to hear voices that others don't hear, voices saying very bad things. I can't imagine living behind locked doors at in the hospital psychiatric ward, or being given new and different drugs daily by new and different doctors and nurses. Or the unstoppable urge to put the knife to the wrist when it is in sight. I just know I want these things to go away, and I can't make that happen. Susan pleads with me for things that aren't there.

However, as I talk with my team and other coworkers, I am constantly reminded of all that Susan has. She has an incredibly strong and reliable community. She has friends to call, to lean on, to visit, to laugh with. Yes, I tell myself, things could be worse. Susan could be all alone in her struggle to regain her mental health.

Back in the kitchen the phone rings and I cringe. "Are you home?" Mike asks before answering. "Yes, I'll take it" - this has become a nightly ritual. It's Susan's friend Jenny. She has something to share and I sit to listen. "I'm concerned about what's going on with Susan," she says. "I haven't seen her in some time, but she calls me, and I want to help. I want you to know my home is open to Susan, even permanently. I want her to feel she's a member of our family. We have an extra room, she knows my family, I'm involved in the church, it's a hospitable town..."

My mind races and I feel myself smile. We discuss some concerns, but as we say good-bye I disregard the details and bask in the beauty of the exchange. Community shines through the grayness of my responsibility, setting me free. Among the complexities of roommate recruitment, SSI-E, Supportive Home Care, psychiatry, meds, and mental illness, hospitality lives. I am reminded of why we are here.

Mike returns to the kitchen. "Is everything OK?"

"Oh, yeah, I'm so glad I took that call. Wow. What a story to tell."

Susan's struggle continues, and her community of friends remains strong. Though it's far from over, the power of that circle of people keeps us moving forward.

A few nights ago, Susan and I were having dinner when she looked at me to speak. Tears welled up in her eyes. "I bet you wish you had lots of people working with you so you didn't have to do this all alone." I sit back, taking in the impact of her perceptions. "I have people to talk to, Sue; people at Options care about you and people ask about you, and help me when I'm confused. I'm not alone."

As I drove home that night I began to realize how much I needed to be reminded of my community too.

February 1990 –Maureen Quinlan

Staff members may find themselves developing connections to people through their relationship with a person they support. Sometimes staff expand communication by interpreting on behalf of the person they support.

Dear Marie,

Ted and I have been talking about what he would like to give you and Duane as a wedding gift. Ted suggested a kick in the seat for you, and a warning to get out while there is still time for Duane. I thought this letter might be nice.

I don't know if Ted ever says it to you, but Ted loves you very much. I have heard and seen Ted's love for you expressed in many ways over the last few months. Ted talks about you and Duane frequently. Sometimes it is to tell jokes and kid around about his relationship with you, but often it is to tell stories about good times he has shared with the two of you and your dogs.

Sometimes Ted tries to make us believe he doesn't care, or that he does not want you to be a part of his life, but his behavior usually gives him away. I see his eyes light up and his whole face change when we talk about plans for you to get together. I see Ted gladly tag along with me through Hilldale trying on and buying clothes he doesn't want to buy in order to attend your wedding. I see Ted express his desire to be a part of your life, and to have you be a part of his life.

When Ted was in the hospital, and very ill, I would talk to him about you, and let him know about conversations we had. I told him what you were thinking about, and when you planned to visit. Ted would always light up and pay close attention. He would often repeat what I told him, speaking with expectation and sounding as if he didn't quite believe what I told him, but wanting to believe it - that you were thinking about him, worried about him, and planning to call and visit him.

Ted was talking about the time when he was at University Hospital in the coma. I asked him if he remembered anything about that time. He insists he remembers you, Marie. He remembers hearing your voice, talking to people in his room. Maybe that isn't significant, but it seems significant to me that the only thing Ted remembers, or cares to comment on, is the sound of your voice in his room.

Ted can be belligerent, and may not hold up his side of the relationship on his own, but Ted loves you. And he wants to be a part of your life.

Congratulations on your marriage. I hope that you have years of warm and loving times ahead of you. Ted also told me that he is very excited about seeing you be married, and that Duane is a pretty good guy.

Warmly,

Kim Turner

Happy Birthday

I hadn't been working at Options for more than six weeks when I learned I was to become Jean's case manager. At first I was so full of concern about my untried abilities to accomplish this feat - despite assurances that it wasn't too difficult - that I was missing the cues of the drama that it entailed.

We talk and think much here at Options about the impact on the people we serve of their being surrounded by paid persons who come into and go out of their lives with their having little or no control over the matter. It's perhaps important to also consider that relationship flourishes or flounders quite oblivious of money changing hands and that relationships are an equality beyond other considerations.

As I thought about this with respect to my new relationship with Jean, I noticed that this new arrangement was having an affect on Sid and Jean. And that Sid was perhaps feeling the same sense of loss, beyond his control, that we generally attribute to those with whom we work.

I went to Jean and asked if she would like to have Sid work on projects with her and Jean said, "Yes, she would like that." But as I conveyed this to Sid I knew that it didn't quite put to rest the concern about the severance of relationship.

Last Thursday Sid and I arranged to see Jean together. I arrived first and Jean had a new Yamaha keyboard on her chair which she proudly turned on. It played for us and we giggled with delight at Jean's new toy. Beth then suggested she play for me the song she had been practicing for Sid. But Jean wanted to save it. She had been practicing all day.

When Sid arrived Jean had her back to Sid so he couldn't see the keyboard. Jean turned on the Yamaha and began to play. Without a flaw she serenaded Sid with Happy Birthday. Jean was very pleased with her accomplishment and very centered on the importance of a person in her life.

Although the new conditions of reorganization may alter how much we see others or even if we see them at all - it doesn't alter how we feel about one another or the importance of the relationship, because that's something beyond the reach of those conditions if we can listen to the songs we have in us that sing about how we feel about one another.

November 1988 –Ellen Backus

Some connections develop from invitations to get involved, others grow out of paid relationships. Like other beginning friendships, these relationships change with time and circumstances. Understanding these relationships takes experience and reflection. What seems sure one month becomes less so the next.

Joe's People

When I first started working with Joe he was a pretty unhappy person but he was not able to articulate that and it took us a while to figure out what was going on with him. He was living with another person Options supports and a person paid to live there. He spent a lot of time in his bedroom. He was reluctant to talk to people, go places. He had quit one of his jobs. He was doing some goofy things, taking small amounts of money, hiding when people came to see him. When we would talk to Joe he was very agreeable and pleasant. Everything was OK. He would return the money. He would take an art class. He would get to work on time, stop staying up all night, anything we suggested was OK with Joe. But his actions and our conversations did not coincide.

I went to talk with Joe's boss. He'd known Joe for ten years. They were friends. I hoped he might be able to help me understand Joe better. Don turned out to be this amazing man who, in the middle of his work day, listened to my concerns about Joe, called Joe's co-workers off their jobs and into his office where he asked things like "What's going on with Joe? Does he seem happy? Is anyone going out to lunch with him, going out after work?" It was obvious that people cared about

Joe. Camille, a co-worker, thought Joe seemed depressed lately, he seemed tired when he came to work. She thought he was doing lots of little things to get her attention. Don asked what people thought of Joe moving into an apartment above the place they all worked with Jesse, another co-worker who was looking for a roommate. People thought that might be a good idea.

I met Jesse and I was concerned. Jesse was not the typical foster sponsor type, whatever that means. He was a musician who worked for Don to survive. He did not conduct his life in the most traditional fashion. But he was very enthusiastic about living with Joe. Joe was a friend. It would be great living with him, he said. "Is there anything I should know about Joe? Is there anything he can't do?" he asked me.

I talked to Joe about moving. "Yes," he said, he would like to move. Yes, he'd like to live with Jesse. But Joe had been saying yes to everything I'd asked him and I didn't know whether he was saying what he thought I wanted to hear or what he really wanted. I felt awed with the responsibility of what should happen for Joe.

I called his mom to see what she thought. She was very concerned about Joe's reclusiveness. She found him very withdrawn, thought he was very unhappy but she, too, was awed with making a decision about Joe's living situation. She thought maybe he should come home, maybe being on his own was too hard for Joe.

When I thought about who else to ask I found I could list ten people on a piece of paper who cared about Joe and knew him much better than I did. I decided to invite them to meet as a group and together maybe we could come to some conclusion about what should happen for Joe. I was quite sure all ten people wouldn't be able to come. I knew that those who would come would only be able to commit an hour of their time. All ten people said yes immediately. The meeting lasted two and a half hours. People shared stories about Joe. They shared concerns about Joe, dreams for Joe. People offered to change work schedules to spend time with Joe. One person wanted to take Joe to his club to exercise twice a week. He said it would make him better about going. Another person said, "I can't believe Joe has no friends. I gave him my phone number and when he never called I thought he wasn't interested." The group was in favor of Joe moving in with Jesse. They felt it would put him in closer contact with his co-workers. He would be more likely to do things socially with people.

Don asked about a boy Joe had lived with as a foster brother for sixteen years. He said Joe talked about him a lot. Someone else knew this person and it was decided we should look into getting the two of them together.

At the meeting we also discovered Joe's sister and her family were planning to move into a house a few blocks from the apartment in which Joe and Jesse were to live.

After the meeting people lingered in the hallway shaking hands and feeling good. There was something very powerful that had happened and people were reluctant to let it end.

I called Joe's parents the next day to get some idea of how they felt about decisions that had been made by the group. Joe's mom said she was very touched by the meeting. She said, "Joe is our son and we have to love him, but I can't tell you how good my husband and I felt to sit in that room with all those other people who care about Joe. We couldn't believe how many people were there."

I asked her if she was comfortable with Joe moving in with Jesse and she said, "You know, you have an idea in your head of what someone should look like and I was a little taken back by Jesse's long hair. He just didn't look like what I thought he would. But what a person looks like isn't important. What's important is who he is and maybe Jesse is the person to help change some things for Joe. I don't know, but let's try it."

Joe moved in with Jesse and some pretty magical things started to happen. Jesse didn't cook at all and Joe turned out to be a pretty good cook which wasn't apparent in his other living situation where he spent all his time in his bedroom. He started making meals for his roommate and Jesse

started eating at home. Joe became a giver rather than a receiver. Grocery shopping with Joe was amazing. He filled his cart with fresh vegetables and fruits and meat and fish and spices and sauces. He and Jesse prepared lists ahead of time. By the third week I was no longer involved in the shopping - Joe and Jesse were doing it.

Joe started going back to work after lunch instead of watching soap operas all afternoon and in the evenings he either went to band practice with Jesse or went to work out at the club with Tom or went over to his sister's house or stayed home and brought food downstairs to his co-workers who were working late. He called his foster brother, the boy he'd lived with for sixteen years and grown up with, the boy he hadn't seen in over six years. I dialed the phone and listened to him say, "This is your long lost brother. I live in an apartment with a friend. I still have my Elvis poster and some pictures of you." Then I left to allow him his privacy.

My reaction to Joe's new living situation was surprising. It was difficult for me to relinquish control and trust Joe's community. In the first week or so I wanted to stop the whole thing. I was afraid people wouldn't be good to Joe. They'd take advantage of him. They'd leave him alone too much. He seemed so vulnerable to me. I needed to be his protector. Against what? I'm not sure. People at Options would encourage me to trust community. They'd say, "These are Joe's people. This is Joe's community. What could you possibly do in two or three hours a week to replace that?" I struggled with what my role was in this living situation. That was never clearer than the evening I met with Joe and Jesse to strongly suggest some scheduling procedures. I wanted Jesse to record on a calendar the days he would and would not be home for lunch, for dinner, and in the evening. Jesse said that would be very difficult. A lot of times he didn't know he'd be working through lunch until the last minute. His evening plans were pretty spontaneous. I persisted. Would he please try to do it anyway? Jesse said he liked me alright but he had problems with me coming in there with my social worker mentality telling him how to conduct his life. He said he didn't want Joe to be unhappy anymore than I did but he thought he and Joe could work it out just fine without specific instructions. It was clear to me that I couldn't have it both ways. The community is not run like the human service system. I ended up expressing my concerns that Joe not spend too much time alone and Jesse said he'd shoot for spending 4 - 5 evenings a week with Joe.

The people in the circle had come together around their common friendship for Joe . Out of that common bond they began to interact among themselves. Jesse got Joe's sister's fiance a job at the place he worked. Tom took some videos over to Jesse to have remade for Christmas presents. Jesse played tapes of his band for Tom. And that's only the stuff I heard about. I'm sure they don't feel they need to tell me everything.

This is not the end of the story. As Sid said, "There is no beginning, no end, only change." The change is in Joe's life and the lives of the people in the circle and the change is in the way I think about my job and in my attitudes toward community. This is new stuff for me and I'm stumbling through it but I feel encouraged that what's happening in Joe's life and the lives of his community will far outlast any role I might play in Joe's life.

One more small story.

Joe has a cat he calls Big Guy. Joe is not always sure how he feels about things but he always knows how Big Guy feels. When Joe first moved in with Jesse he said Big Guy was very scared and that he was hiding under the covers in Joe's bed. But Big Guy came out of hiding within a week of his move and now he's doing good most of the time.

December 1988

–Kathy Lemke

Thoughts on Community Building

I have been thinking about community building, mostly because of Cathy and Joe. And I guess I've learned that building community does not mean setting up a situation and walking away from it. Instead it means a different way of providing long term support.

Cathy moved into the top flat of a house owned by Gary and Cheryl last September. They had come to Options looking for a tenant. They wanted to rent to someone needing some companionship. Cathy's first several months in Gary and Cheryl's house were difficult for her. Gary and Cheryl were consistent in their support. Every time I thought they were going to evict Cathy or say, "You didn't tell me this!" they surprised me. The relationship between Cathy and Gary and Cheryl grew and I watched Cathy become more secure, more relaxed, more sure of what to expect out of her life. Gary and Cheryl and I didn't particularly click. We never seemed to get beyond role playing with each other. But fortunately they felt very comfortable with my co-worker. I began to hear wonderful stories about Cathy and Cheryl going to parties together and sharing meals, Cheryl helping Cathy get to work on time, Gary inviting Cathy down for dinner, Cathy helping Cheryl paint her kitchen, bits of stuff that sounded good and natural.

Then Gary got offered a job in California. He left in March and Cheryl joined him at the beginning of April. I don't know how Cathy felt about them being here one day, gone the next. My guess is it was hard for her. She was able to stay in her apartment and by the time the Johnsons left she was living with a roommate she likes very much and her boyfriend, Jim, was a frequent welcomed guest. But a valuable relationship in her life was gone.

Other Thoughts on Community Building

The community is not run like a human service system. It is not systematized. It does not have prearranged goals and objectives. When we are trying to enhance relationships for a person with a disability we more often than not fail if we do not meet people where they are at and listen to what they feel comfortable committing to and what they do not. People will often be comfortable with the fact that we are available for their questions, ideas, and concerns but be uncomfortable if they perceive we are trying to control how they live their lives or what they think.

Community isn't built by having a meeting or drawing a plan on paper with colored markers. It is built by connecting with people on a personal level. Every contact is different but each time we ask a person for their input or present a person with a disability in a respectful and human way we make a relationship more likely to happen.

The role a human service worker plays in the life of a person with a disability and his community is a delicate one. If the community members feel they have no input, no decision making power they will not be invested. If they feel a person's welfare is entirely their responsibility, they will be overwhelmed and frustrated with the lack of help.

These are all thoughts I've had around Joe. His living situation is changing again. His roommate, Jesse, wants to move in with a girlfriend. Although he has asked Joe to move with him, Joe does not want to do that. When I talked with Joe and Jesse about the situation I told them what I thought I could do - advertise for a paid roommate. Jesse was not satisfied. "I don't want Joe living with a stranger. He doesn't need a baby-sitter. He needs someone who will be a friend, who will treat him like an adult." Jesse went on to talk about the changes he's seen in Joe the last six months. Joe listened. He liked what he was hearing, I think. I asked Joe to think about all the people he knew. Was there anyone he wanted to live with? I asked him to think about what he wanted his next living situation to be like. I did not say that Jesse hadn't lived with Joe very long or that their living together for seven months had not worked out. From the human service standpoint that may be true. In human service plans foster sponsors do not meet girlfriends, fall in love, and move in with them. But in communities that is what happens.

When I saw Don and Beth at a party I told them Jesse was moving out and that Joe was looking for a new roommate. Beth was disappointed it hadn't lasted longer. Don said he'd seen a lot of

change in Joe. Joe appeared more self-confident, more direct, happier. Beth thought she may know someone looking for a roommate. Instead of assuring them I'd be able to set up a new living situation I asked them to think about what would be a good next step for Joe.

I ran into Camille on the street. She was upset that Joe was not moving with Jesse. She thought living with Jesse and his girlfriend would be good for Joe. She also wanted me to encourage Joe to join Special Olympics. She thought he could meet more people that way. She told me she cares a great deal for Joe and she thinks he is so much happier now. I didn't agree with everything Camille said, but instead of telling her that, I asked her to talk to Joe about her ideas. When I told her I'd be in touch she said, "Call me anytime."

Tom called late one night to tell me Joe had asked him to move in with him. Tom said he was considering the move and had some questions about what his responsibilities would be. I asked Tom what he thought. Tom talked about companionship, about how living with Joe would benefit them both, about the importance of his independence. I told Tom I'd strongly support his living with Joe and help any way I could if that was what he and Joe decided to do.

Jesse, Beth, Don, Camille, and Tom are all Joe's friends. The human service system would call them Joe's circle of support. I have no idea how this will play out, but I am hoping Joe will find a new roommate the way we all do, by talking with friends. And I am certain that his living with Jesse was a good thing because it was what Joe wanted, the way he wanted it. And for the time being, anyway, Joe and Jesse will still be co-workers. But just as in Cathy's life, it is change and fractured relationships and I guess that, too, is part of community.

This stuff is hard. It is easier to hire people and systematize living situations.

May 1989 –Kathy Lemke

Intimate relationships are as important, as fulfilling, and as confusing for people with disabilities as for anyone else. Support workers may have to figure out how to support people in the context of close relationships.

Romeo's Here

As I pull up to 148 N. Lakewood I glance at my watch, it's 3:30. Good, now I'll have about fifteen minutes to talk with Carolyn before Jeff comes home from work. Walking to the door I wonder what they will argue about today. They always seem to argue whenever I see them together.

I knock at the door and a damp, towel dried and uncombed head appears. "Well, Diane, what a surprise," Carolyn says. Then she puts both of her hands to her head and says, "Don't look at me. I just took a bath and am doing the dishes!" I apologize for being early and we talk. She tells me that Leslie came over for lunch today.

At 3:45 we hear a key opening the front door. "Romeo's here!" shouts Carolyn. Jeff enters the kitchen, home from a hard day of dish washing at the WPS kitchen. "Look at your shirt, yuck!" says Carolyn. Jeff asks her if she saw the note about going to his mother's for the weekend. Carolyn told Jeff his mother could come and stay with them on Friday night so she wouldn't have to drive over on Saturday morning to get them. Jeff said he would ask her.

"Hey, Jeff, I'm doing dishes. Ain't that a shocker? I can't get this popcorn bowl clean." "Well, that's because you don't use your muscles," Jeff joked. Then he said to me, "I usually do the dishes around here."

"What do you want for supper?" Jeff asks.

"Oh, I won't be here. I'm going to an exercise class with Kim at 7:00."

"Well, I want to make something you'll like so you can eat when you get home."

"Well," said Carolyn, "you can't have any macaroni and cheese."

"You and Leslie ate four boxes of macaroni and cheese for lunch?!"

"No! We had soup. I put the macaroni and cheese on the top shelf because you're saving it for Sunday. Kim said I should wear sweats to the exercise class but I don't have any. She said to just wear loose pants. I wonder how loose do they have to be?"

"Well," Jeff said, "loose enough so they don't fall down when you're jumping up and down."

"I'm only going to absorb the class tonight." "What?" Jeff asks. "Absorb it, you know, watch."

Carolyn tells Jeff to go upstairs and change. When he leaves the room Carolyn opens up her check book and shows me a $40.00 check. She whispers that this is for Jeff's birthday present. Tickets to see Barry Manilow. I thought she was going to explode all over the room she was so excited.

Later as I left I realized I was smiling. I guess they're not doing so bad after all.

March 1988 –Diane Steele

I Want...

I'm lonely - I don't have many friends. Most people don't like me because I don't act very friendly toward them. I don't really care, but I do want to have a boyfriend. I want to get married and have a baby. I know I can't really take *care* of a baby, but I really *like* babies. Most of the people I know get married and have kids.

I want my boyfriend to be strong and to tell me what I should do. I want to be loved. I want a boyfriend who will put his arm around me and hold me and kiss me. Nobody does that, you know? I want to sit and watch TV with my boyfriend and just hold hands. I want my boyfriend to care about me.

I want to have sex with my boyfriend. I want to know what that feels like, and I want to make my boyfriend happy. I want to feel better about myself and having a boyfriend will make me feel I'm as good as other people.

My boyfriend won't use a wheelchair; he will be able-bodied. I want a boyfriend who can do things I can't do. If we were both in wheelchairs, what would we do? I know that none of this will probably ever happen, but I want it to. I'm going to try to make it happen.

February 1991 –Kim Turner

Julie's and Wayne's Dream

"In community people are as they are, with opportunities to follow their dreams.

In community, relationships are reciprocal, give and take...

...people seek answers from their own experiences and the wisdom of others...

...people can make honest efforts and acknowledge honest mistakes and fears...

In community, there is room for confusion, and mystery, and recognition that some things are beyond human control."

Mary O'Connell relays these thoughts to us in the book *The Gift of Hospitality*, and these thoughts come to mind for me as I considered this story which unfolded this past summer.

It was a long time coming, I was told by Wayne as he and Julie shared with me the plans for their wedding.

They had met several years ago while Julie lived in a group home and Wayne lived at [a local facility]. They were introduced, soon shared a dinner, and have been together, essentially, ever since.

Time went on bringing Julie and Wayne out of their respective "residential settings", and together to share a home. I didn't know Julie and Wayne at this time, but I do know that this was Wayne's first place he could call his own, and Julie had been out not too much longer. No doubt many challenges were faced, and overcome, as they learned the give and take and ups and downs of sharing a home. But through it all, Julie and Wayne continued to dream. To each of them marriage was very desirable. They talked of it often. It was normal, it was what couples do, and it was something they feared they would never have. Particularly Wayne, feeling anxious about the passage of time and anger at having so much of his life taken away from him. Difficulties resulted in the two moving apart, but again, Julie and Wayne continued to dream.

In winter of '89 plans began to solidify. July 15 was set as the date, and invitations were written out in February. Together they found a pastor to perform the ceremony. They found some rings, debating and resolving who would pay for them. July drew near. Rings were purchased, the license was applied for, and a box for wedding day donations was prepared.

In spite of my involvement in their checkbooks I truly realized my importance in their lives as they informed me of these accomplishments and continued to deny my offers of assistance. There was no place for me in this process for Julie and Wayne. Why did I think there would be? I guess I really just wanted to be a part of this realization of a dream. My final request was to attend, and this was granted.

Along with the planning and anticipation of the couple came a flurry of concern and panic in their community. This was revealed to me in the form of telephone calls to Options. Calls from Mom, from sister, from the County Clerk's office, from Social Security and from the pastor. The calls were at times demanding, inquisitive, concerned and humorous. Some wanted me to do something about what was to occur and some wanted my expert opinion on this decision. Of course I would be as much a part of breaking up this union as I was the joining of it.

Well, as things go, July 15 came and went. Another date was set, which also came and went. Plans changed, they announced, they don't want to get married yet, they're not ready. Perhaps pastoral counseling and/or family pressure aided this decision, perhaps not. While I felt for their disappointment and sadness, I felt a satisfaction realizing these were truly Julie and Wayne's decisions and not the system's. Now they continue to enjoy their relationship, and continue to dream.

This isn't a particularly happy story, nor is it a particularly disturbing story, as many told here are. It is just people, experiences, relationships, decisions - it is real life.

October 1989 –Maureen Quinlan

Money Matters

Poverty shapes disabled people's lives. Poverty forces hard choices that seem harder because they make luxuries of everyday extras like a picture of one's friends or food for a pet. Poverty occasions staff control of some people's expenditures because poor money choices easily lead to crisis when at best one has only the thin cushion allowed to a person who receives income support and medical assistance from government. Poverty opens one's life to the scrutiny and criticism of strangers who believe that they know what conditions poor people should gratefully accept. Like Dan, most people adopt a conservative approach to managing their money. But a few people, like Randi, model themselves on more affluent consumers and live as far beyond the edge of their means as their creditors will allow.

Poverty

While talking with one of the Ashland visitors, she asked me what is the hardest thing our folks have to deal with. Without hesitation I said poverty. It affects every aspect of a person's life. I thought more about that the next day. I thought of my conversation with Dan that week.

"Well, Dan, you've paid your rent, your MG & E bill, and written out your check for groceries. That sure doesn't leave you with much money."

"Oh, I need a bus pass, too."

"I'm sorry, Dan, but you just don't have enough money for a bus pass."

"I have to have a bus pass. It gets cold in October and I can't ride my bike then."

"Well, OK, if you pay your cable bill late you can afford a convenience ticket."

"I also need $12 for a season basketball ticket at LaFollette and money for my sorority's yearbook picture."

"Well, you just can't afford either of those things. You can get the basketball ticket next month and the sorority picture in December. You are probably going to have to cancel cable and HBO, too."

"I can't get rid of cable or my TV won't work. It will only run on one channel without cable."

"Well, one channel is better than no TV at all."

"Diane, I like to watch TV in the winter. I can't just watch one channel." He then proceeded to unhook the cable to verify his argument.

"Yep, you're right, you only get one channel. With the hot summer over, your MG & E bills will start to go down, and you will be getting Energy Assistance. Maybe we can work something out so you can keep cable, but HBO will have to go."

"OK, what about my subsidy?"

"You should be at the top of the list."

"I get to stay at Park Towers, right?"

"I don't think so. The rent is way too high."

"But I like it here."

"You know, Dan, a job would help."

"I don't want janitorial, I want dishwashing."

After several more minutes of conversation I left. I was angry, not at Dan, but at poverty, at Dan's situation and the many other people that we serve who are in the same boat. Oh sure, Dan could get a job that would help out with the extras like a basketball ticket, a sorority picture, a bus pass. But then a bus pass shouldn't be an extra.

November 1988 –Diane Steele

Disposable Income

The talk of big bucks from suing [the pizza place where Randi worked] was getting on my nerves. Each month it was the same thing... "Well, the court date was changed. I have to go to another doctor for his opinion. My lawyer thinks we'll get $10,000. Do you think Options can loan me $100 till I go to court?"

It was getting hard for me to believe that Randi would ever see a penny from his workman's comp claim against [the pizza place]. He was suing them for injuries suffered on the job. All of the lawyers, doctors and dreams about all the money seemed just like that... a dream. As usual, Randi was commandeering the legal ship... I was only privy to the moans and complaints... oh, if the world only ran like Randi wished.

Finally, on August 10th, Randi went to court. He walked away with a check for $867.00 and with, as he puts it, "More to come, we go back again in September."

Now the typical finances for Randi go something like this. $500 in on the 3rd of the month, $500 out on the 3rd of the month.

"$102 to J.T. Curran"

"$75 to J.C. Penny's"

"$50 to Boston Store"

"$50 to Wisconsin Bell. Do you think I can skip MG & E this month?"

"NO"

"OK then, $24 to MG & E. How much do I have now?"

"$201"

"$82 to HRSI. Where am I at now?"

"$123"

"I need 80 for Woodman's"

"You're down to $43"

"$6 to Walgreen's"

"OK, it's at $37"

"$28 to Madison Metro"

"OK, you got $9 left"

"Did you take out my $2.50 to the Animal League?"

"No, OK, about $6"

"Better leave that in there."

But the day the workman's comp claim check came it was a different story.

"I put $700 in the bank and kept out $167."

"OK"

"How much do I owe Options? " (A quick call to Polly revealed $175.)

"$175 to Options"

"$100 for cash"

"$9 for TV Guide"

"$10 for the Grocery Saver Club"

"$30 to Golden Press"

"$20 to WWF Magazine. How much do I have?"

"$345"

"Better pay my cable bill. That's $19.37."

"$2 to Seattle Film Works"

"$6.97 to Magazine Market Place"

"$20 to Pet Plus"

"$33 to Silhouette Services"

"$11.97 to American Publishers"

"$62.34 to Publisher's Clearinghouse"

"You're down to $160"

"$29 to National Lampoon"

"$38 to my mom"

"$47 to the Pet Health Clinic. What does that leave me?"

"$48

"Better leave that in."

Driving back to Options I was amazed. $700 just like that. $1,700 outstanding on the J.C. Penny's card. Who knows how much to Boston Store, HRSI, Wisconsin Bell, MG & E? If it was me I would have paid my bills and kept the rest for next month's bill.

Last night I saw the movie *Dead Poets Society*. "Carpe diem" "Seize the day".

Randi lives on $500 bucks a month twelve months out of the year, year after year. It's hard for Randi to live by the philosophy "Carpe diem" at least financially.

Dylan once wrote, "Money doesn't talk, it swears." Randi swears he needs more money.

$867 in August, more in September.

Hey Randi, better order more checks.

September 1990 –Sid Nichols

Sometimes the tables turn on those whose competence entitles them to be in charge of another's financial decisions.

Don't Use the Candle

I walked into Peter's apartment at 9 a.m. sharp. He said the checks I needed to sign were on the table. I reached out - grabbed his candle stick and soon realized that it is next to impossible to sign a check with a candle. Peter roared with laughter. As a matter of fact, yesterday when he called to remind me to come over on Thursday he said, "Sid, I put some pens on the table for you... but whatever you do, don't use the candle."

February 1989 – Sid Nichols

Fighting the System

Most of the people Options supports rely on other parts of the human service system for essentials. Cash for basic living expenses comes from the social security system and from housing assistance programs. Access to and support for meaningful jobs depends on the policies and competencies of day services agencies. The ability to get around depends on the accessibility of public transit. Funding for necessary assistance –including Options' agency budget– comes from a variety of state, federal, and county disability programs which are administered by the county government. Along with a great and growing demand for paperwork, this complex and scarcity plagued system embodies a confusing mix of policies. Positive initiatives coexist with stigmatizing practices that clearly promote dependency and segregation. Unless staff members ally with the people they support to continually fight the negative effects of the human service system, that system will crush the life out of all the people who rely on it for their living, both people with disabilities and staff people.

Humor introduces a distance that keeps the system from taking over people's minds.

The ABC's of Clienthood

"Welcome to the Human Services. I'm a Human Service Professional, or HSP. People like me help people like you with problems. Now what sorts of needs do you have? What's wrong with you? What's your disability?"

"Well, they say I have a developmen—"

"Aah! DD. What is it, MR? CP? TBI? Or is it a dual diagnosis with CMI? If it's a dually diagnosed developmental disability, or DDDD, then I'm afraid you're in real trouble. People with problems—PWP's—often have several awful things simultaneously. But there *is* hope. Why, we have M.S.W.'s, B.A.'s, R.N.'s, M.D.'s, even QMRP's, that can fix you up with an ISP and a PPOC in a jiffy. Heck, before you know it, you'll be headed for NWC, CWC, or SWC!"

"Aren't those institutions? I just want to find an apartment and a job. And I want to meet some people."

"Oh, you'll meet lots of Special People, S.P.'s. Around here we'll treat you like a VIP. Now if you really think you can function at a high enough level to live in the community, well, we can still help you. That's what we're here for! We'll get in touch with UCP, the USB, ARC, CCLS, CHA, REM, SLA, RFDF, CDA, DCHA, and there's always an ICF or CBRF. You'll need VNS, RRC, AMI, MA, COP, CIP I, III, V, and VII, WTA, DHSS, and AA. You'll be entitled to SSI and SSDI. And while you couldn't afford a BMW, an RX-7, or a ZX even if you could drive one, you poor thing, you can get a nice black and white G.E. TV with CBS, NBC and ABC. You can go to A & W, PDQ, and M & I where we'll set you up a two signature account and make sure you don't spend too much of your money.

"You know, maybe this human service thing isn't for me. I mean, maybe my family could help me find a job and a place to live. Besides, I don't think I like your attitude."

"Now honey, I feel sorry for you. I really do. I'm just trying to help. Now then, we'll have one of our vocational providers plug you into a job somewhere ASAP. Not for pay, and probably just a few hours a week, so you'll have plenty of time for R & R. Let's see, there's MOC, DVR, VEA, RES, CWS, CVS, VCS, VOICE, WORC, MARC - and more and more every day. You won't be working for IBM, AT & T, the CIA or the FBI, but at least you won't have to worry about the IRS. No, you just leave the worrying to the Human Service Professionals - we'll take care of you!

"You forgot something, Mr. Human Services Professional HSP: The Social Security Administration is the agency that would dole out my SSI and SSDI. They're the S.S.A. Reverse those three letters and *that's* where you can stick your ISP, PPOC, and all your QMRP's. Have a nice day!

January 1988 –Peter Bazur-Leidy

Take a Ride on the Wild Side

This trip is not for the timid or squeamish at heart. It's for those who like to live dangerously - add a little excitement to their lives. The quality of one's mobility experiences cannot be complete without first taking a ride on the wild side - a ride with driver 2421.

Driver 2421 is a [paratransit] bus driver. One would know this only because of the official patch on his arm and the fact that he was the one behind the steering wheel. I don't mention a uniform as it didn't appear that he wore one. There was the typical brown slacks and jacket, but somewhere around the waist area, this large bulky black undergarment was hanging out over his horrendous stomach. Not that I care to know what it was, but it certainly wasn't your typical boxer shorts - I don't think. He wore a stocking cap, one of the hunter orange variety with a deer emblem on the front. His shoes resembled the boots that my dad wears to clean the barn. Obviously people who drive a bus and make $10.00 an hour aren't to be bothered with a dress code.

As for his personality, I don't think he had one. He said very little to any of the passengers, but had a great deal to talk over with himself when the lift gave him trouble. His face was set in a sort of sneer that he openly shared with all. From my vantage point at the rear corner of the bus, I was fortunate to watch his face in the rear view mirror for the entire 50 minutes that I was enjoying the ride.

Now don't get me wrong - he did his job. He made sure that all of the riders in wheelchairs were secured down. He checked that all other passengers wore seat belts - all that is, except me. The seat belt where I sat would have fit around sixteen wheelchairs, and I struggled to shorten the belt. When he saw I was having trouble, he waved it off. I wasn't a paying customer anyhow.

A lot of miles can be covered in 50 minutes, considering we made four stops before reaching our destination. While I think nothing of going 65 miles per hour on the interstate in my car, going that fast down the 1/2 mile stretch of highway 30 and still making our turn-off, well this gave me something to think about. I guess there's a schedule to keep.

During the entire trip, the bus continued to make these loud creaking and groaning noises from underneath like I've never heard before. It was certainly straining. Why did I need to worry about a seatbelt when the back of the bus was about to break off from the front at any moment? To make the ride even more enjoyable, the bus was not equipped with shocks. None. And driver 2421 made every attempt to hit every crevice and pothole in both traffic lanes. And the thing was, he always seemed to be sneering at me in that mirror after every jar - knowing that my seat over the left rear tire was not one I'd have had to fight to get.

Was I being hysterical, paranoid? Did this man have it in for me? I'd never met him - believe me, he was the sort one would never forget. Everyone else on the bus, which included five other passengers, sat passively by as if nothing were going on. Was this a typical bus ride home after work - your basic transportation? Or was I fortunate enough to ride with that someone special, driver 2421 - an experience that one can only pray does not happen on a daily basis? It only re-affirmed in my mind that I am indeed lucky to not be totally reliant on the public transportation system. Next time I pay the car repair bill, I think it won't hurt as much.

March 1988 –Alice Sosinsky

Neat Little Boxes

It probably all began back in Cro-Magnon societies. One day a tribal leader decided that the clan was too chaotic. Why, there were dead animals here... dead animals there. Rocks were scattered about... there was no order in the leader's mind. Since disorganization breeds organization the tribal leader set out to organize the clan. Pretty soon there was a place for dead animals, organized by size and species; rocks were neatly piled. The leaders lived in one part of the cave, the healers in another

and so on. Everything, in the leader's mind was in "neat little boxes". If paper had been invented I'm sure a form would have followed.

It was Moses, however, who delivered the first "form" to modern society. It was on a tablet, legal sized I'm sure. The form gave all people the ten basic rules to follow; it was organized so that either people were sinners or not sinners, check the appropriate box. However God soon found out that forms and rules are only productive if there are consequences for not following the forms and rules… and wa-la, hell was born.

Next in our historical linkage came the Social Security Administration. An "organization" raised on the axiom if two forms are good, five thousand are better. It is here in history that I believe that organization and organizations that are systematically organized became poor bedfellows with ordinary life. You see we can't all live our lives according to the rules and boxes set forth by others. Granted there are certain things you can never escape, like, say, how Woodman's is organized. However, for people who are in "special" systems due to their labels there tends to be hundreds upon hundreds of "neat little boxes", rules to live by (the golden rule is always thank your case manager for taking you shopping for underwear), forms to fill out and categories to fit into. Some examples:

-When the person seizures do they froth at the mouth?

-Check the highest eligibility level

-Check the level of independence

-Is person aware of personal needs?

The list goes on and on.

An important distinction to make here is something quite profound. As a matter of fact, it should probably not leave this room. *People's lives continue to go on even without forms, neat little boxes, and rules.*

That's right, those forms, "neat little boxes" and rules are entirely for our benefit. The luxury of being organized is ours. Why do you think they call us an "organization". We do not want our work lives filled with mayhem and chaos so we become organized, just like the Cro-Magnons. Now organization and neat little boxes in and of themselves are not bad. Not bad as long as they provide the means to accomplish our goal of getting people connected and empowered. The danger is when "being organized" becomes the end. When we become consumed with trying to make a "service" based on choice and autonomy, the ebb and flow of life fit into "neat little boxes" where forms and rules take on the primary importance.

A couple years ago Peter bounced a couple checks at the bank. The bank required him to go on the "double signature system" so that I could monitor his money and make sure no more checks were bounced. All is fine and dandy, no bounced checks. However, Peter's recent financial strategy is to fill different shoe boxes with checks I've presigned. "I don't want to fall behind my bills," says Peter. I've tried to explain that it really doesn't do much good to have oodles of checks presigned by me sitting in shoe boxes, since I see him every week, and can sign the checks then, when he needs them.

"Jesus Christ, I'm just trying to keep on top of things," Peter yells. My suggestions make him quite nervous. Obviously, Peter has devised a way to organize his finances literally into neat little boxes. It isn't how I'd organize my finances but it makes Peter feel in comfortable control of things.

Our accountant Gary, as I'm sure you all know, has recently given us recommendations on how to be more accurate, safe and responsible when we are involved in people's finances. It's a system of rules and organization, fitting what we do into neat little boxes. Gary's suggestions are good based on an accountant's perspective. However, I'm faced with a dilemma. Clearly Peter's "neat little boxes" of presigned checks and Gary's "neat little boxes" of financial rules don't make good bedfellows.

Whose "neat little boxes" am I supposed to go along with, Peter's or Gary's? Then again, perhaps Gary would like to take over Peter's financial situation for several weeks and see what he comes up with.

July 1989 –Sid Nichols

I Mark the Line

by Johnny TASH

I keep a close watch on this book of mine.
I keep a pen by my side all the time.
It's to the paperwork that my heart is tied.
Keep track of time, then mark the line.

It's so easy to remember, don't forget
It's either training or case management.
The marks are worth four dollars and five cents.
Keep track of time, then mark the line.
Now it's very, very crucial to be true.
These marks just don't come out of the blue.
The auditors they won't have a clue.
Keep track of time, then mark the line.

It don't matter if they're billable or they're not
'Cuz your time it all adds up a lot.
Now we've found that our values can be bought.
Keep track of time, then mark the line.

This song may be silly, so it seems.
But those marks keep bringin' in the green.
And the times have been gettin' mighty lean.
Keep track of time, then mark the line.
Keep track of time, then mark the line.

Spring 1989 –Sid Nichols

Anger at systems that impose unjust and demeaning conditions on people one cares about motivates continuing struggle to maintain strong alliances.

On Our System and ANGER

I've worked at Options for six years now, and I realize I'm angry about our system - the one we all work in, and help keep going. I'm angry that I feel like I can't change it, and so I do little to work toward that goal. I look down the list of names of the people I support - or clients as they are more commonly known by our system. I'm angry about how the system keeps us all down and wandering in circles.

John can't earn enough money in our system to be able to have health insurance, or to take the vacation he dreams of. Instead, our system, and my part in it, keeps him in a one-down position of having to try to manipulate people to have access to his own money. Sometimes I feel angry at John about it - why doesn't he appreciate everything we are doing to help him manage his $420 per month? Why does he screw it up every time we get it straightened out? It's because of our system, and because he doesn't have enough money to live, let alone to play.

Sandy can't go the places she wants to go. It's because of our system. Just because she can't get on a

bus on the corner, or get into a car like most of us, she is forced to be "bad". "Little Sandy was bad again," she tells me before producing a stack of Care Cab bills. I feel angry that Sandy is messing up her budget, (or my budget for her) by calling the only transportation service really accessible to her. Why do I feel angry with Sandy? It's our system that won't provide her with transportation, or enough money to afford the transportation that's out there. It's our system that forces her to be manipulative of others, to lie to get rides, to borrow money she can't repay. All of this just so she can go to a public place to be around people she enjoys.

I'm not angry with Sandy, or with John. I'm frustrated and angry at our system. My head rationalizes for the system. We all have limits on our income, and have to make choices about how we spend it. John and Sandy have to learn that, right? Could I? I doubt it. I'm angry about our system - the one we all work in and help keep going.

I used to think it was good - this system that we are all a part of.

April 1988 –Kim Turner

A Better Survey

A couple of weeks ago I started receiving surveys in the mail from various places that Barb receives services from. Barb and I carefully went through each one to try and get her opinion along with my observations. Just when I thought we had finished the last of them a letter arrived from her day program. Since my relationship with this particular place has never been good, and having been told just a couple weeks before that Barb was in jeopardy of losing her job, I cautiously opened the letter. Much to my surprise it was another survey. Half-heartedly I thought this was great - they actually wanted feedback on their support.

As I began reading through the survey I came to a couple conclusions. One being, if I answered their questions with "No" or "No Opinion" I came off looking like someone who was either completely unaware or disinterested. If I answered "Yes" I thought they were doing what they said and agreed with the ways they go about doing it.

Since the provider gave no opportunity for their clients to give them feedback I decided to come up with my own survey that most people would be able to tell or show us in some way how they feel about their service.

It might read something like this.

1. Do you like being sprayed in the face with water when you bump into or touch another person? (Never mind the fact you can't see.)
2. Do you like being tipped back in your wheelchair while your shirt dries from drooling on it?
3. Do you like taking off from your paid job one Friday a month and not having a choice in the matter?
4. How has the training you've received in picking up blocks helped you to find a job?
5. Do you like time out? What has it taught you?
6. If you have problems at work can you get extra help for a while or do they say you showed us you could be independent once so you'll just have to do it again?
7. Do you like it when staff forget to let you eat your lunch just because you were having a problem at your assigned lunch time?
8. Do staff use communication books you have or make you dependent on them by saying they know what you're saying and they really don't need them?
9. Did you enjoy the three months of training you received in how to write the address of a place you haven't lived at for over a year?

10. Did it make you happy when staff took your money from your wallet to pay for juice and coffee you'd drunk for the last two months? (After all, how were we to know you'd planned to go out with a friend?)
11. Did you know that all that time we were making you do hand pushes against the wall to straighten your fingers we weren't aware you had arthritis?
12. Finally, do you have any suggestions as to what would make this a better place to come to daily - keeping in mind that all the goals we have for you are set after very thorough evaluations in speech, occupational and physical therapy.

Thank you for your continued cooperation.

Day Program Inc.

October 1988

The human service system misuses large amounts of money to isolate and segregate people with disabilities. This makes it even more frustrating to deal with the dilemmas of respecting individual choice and responding to people outside the agency who want and deserve its support.

No Room at the Inn

I have talked to a lot of folks about Options in the last year. I've told them about how Options supports people, all that stuff about people living where they choose and with whom they choose.

Our team talks about changes coming up for people we support. Larry has wanted to have a roommate again and Dale wants to live alone, which leaves Bud needing and wanting a new roommate. Our team feels stretched as far as we can reach in supporting people. How can we do more? Maybe one more person, but not two, or possibly three, if we consider the other element in all of this - a real person needing support named Kerry who is being jerked from Kankakee to Boston by the system.

What do we do? Do we figure out some way that Bud and Larry (who years ago were roommates and did NOT like it) can have regular, everyday, off-the-street roommates who don't need our services? Do we tell them, "Too bad, you need/want roommates! Life is a bitch and we can't support more people." Do we just do it anyway?

Do we hurry along our process of thinking about all those folks on the waiting list and how Options might grow/spin off/expand? The state of Wisconsin is paying $300 per day to keep Kerry in a nursing home in Boston. That is about 20% of Options annual budget. I might be mistaken, but somehow, something seems wrong here. Why don't other people notice?

I've done a lot of things I don't fully agree with because it was my job, but I know I can't tell people that they are out of luck in getting help finding the roommates they want because it would be inconvenient for me. I can't do it. I've thought about it a lot, and I will try to keep myself open to looking at alternative ways to find roommates, but I have to know that I'm doing what I'm doing because it is best for the people we support, not best for me.

April 1990 –Kim Turner

Fighting back against the system is hard because the system reflects and reinforces beliefs that are common among ordinary community members and among disabled people themselves. Fighting the system may well mean learning to disagree constructively with our aunts and our friends and ourselves.

Mr. Fragile-X

At a small family gathering back in my home town, my aunt Joanne, who is a receptionist for [a residential facility], my other human service experience, was telling me of the new developments.

"We only have four residents in Cottage 1 and four in Cottage 2. One of the residents in Cottage 1 is a real problem... a Fragile-X. Do you take care of any Fragile-X's?

My mind raced. What do I say? "Uh—I don't know," was my cynical and caustic reply.

"This guy is a real problem," she went on. "I guess Fragile-X's are very violent. Why he shouldn't even be here. It costs us too much to take care of him. He has to have only male staff... and when he blows... look out... they clear out the cabin."

"Hmm," I said. (Ignore and redirect, ignore and redirect I thought.)

Driving through my home town that night I kept looking around, hoping to get a glimpse of the Fragile-X. Could he be in the arcade, Patsy's Popcorn? I don't think I ever saw him, but I can't really be sure. I'm not even certain I'd know a Fragile-X even if he was staring me in the face.

July 1990 –Sid Nichols

Dear Gary,

Another Jerry Lewis extravaganza has come and gone. I know how much you and your family have always thought of Jerry and his commitment to fighting Muscular Dystrophy. I, too, applaud his efforts, but the man continues to drive me crazy.

Remember I used to tell you how it bugged me the way he talked about "his kids"? The summer I met you, 1982, you were 22 years old. You were one of the youngest people at that camp! The dozens of people with M.D. I met those two summers were ***all*** adults. Once you and the others were children with M.D., but adults with M.D. are out there in large numbers. Jerry is either leaving them out or grouping them in as children when he says "my kids".

I would never question Jerry Lewis's commitment, generosity, and good intentions. I acknowledge and appreciate his efforts. What I don't like is the image he and the MDA put across to the public - the image of people with this disease as helpless, loving children who need our sympathy. I have no problem with aggressive fund-raising to help find a cure for a disease that kills so many people - a disease which brought you and I together and then separated us 2 1/2 years later.

I heard that over a billion dollars have been raised to fight M.D., and that's great. I sincerely hope the many years of research produce a cure. But Gary, with all the media attention and publicity - especially from the telethon - which is needed to raise money, segregation is celebrated, stereotypes are perpetuated, and dignity is left behind, forgotten.

Labor Day's *Parade* magazine has an article written by Jerry along with a cover photo of a cute little boy (why is it never an average-looking kid?) The title of the article, read by millions of people, is "When Courage is Beautiful". It is well meaning, but not all people with M.D. are courageous. A stereotype is a stereotype.

Throughout the article we see more generalizations and labels. "Stricken human beings," Jerry calls people with M.D. "You never hear them speak of pain or discomfort." Hogwash! *Every* person who can ***speak*** speaks of pain and discomfort. He's trying to tell me that these folks always smile and utter only courageous, selfless, and upbeat words. "Each day of their lives," Jerry writes, "they think positive and only uplifting thoughts." I wish he'd let people be human.

I miss you, Gary. Sometimes it was hard to talk with you and be with you because you didn't have a very positive outlook on life. Courageous? Yes. Cheerful? Not really. You didn't complain much, but you didn't hide your pain that well either. You couldn't, because you're human, You didn't fit the stereotype.

You were witty, bright, and bitter. You used to call yourself Archie Bunker and me Mike Stivic the way we'd argue. You had your share of prejudice, as do we all, to some extent.

93

Sorry if this letter sounds like a broken record to you. You've heard it before, and probably still think I'm a raving lunatic. I'll tell you something, Archie. The thought of you, wherever you are, doing cartwheels, riding a bike, taking long walks with those legs you couldn't use the last 18 years of your life - that image makes me forget how irritated I am with Jerry Lewis.

September 1988 –Peter Bazur-Leidy

Art and Its Use in Creating a Warm, Home-like Atmosphere for People with Disabilities Living in Their Own Community-based Homes

The freshly painted walls of Ray and Mark 's home were white and bare. A stock of "art work" (i.e., framed photographs purchased at some place along the lines of Shopko) sat waiting reinstallation on the walls.

Andrew, Ray and Mark 's temporary summer roommate, picked up one of the pictures and asked, rather sarcastically, if he should re-hang the institutional art on the walls.

What's this, I thought? Institutional art in someone's home in the community? How could this be? Why hadn't I noticed before? Image juxtaposition! Right here in our very midst!

I looked carefully, for the first time, at the stack of "art" waiting to be exhibited. They were indeed rather impersonal pictures - a wolf, a fall scene from Anywhere, USA. Hmmm.

Andrew asked, more gently this time, if it would be OK to use the frames to put up more personal photos or drawings of Ray's and Mark 's. Ray jumped at the idea. He grabbed the picture of the wolf and started attempting to dismantle it. Andrew and I quickly warned Ray that his unframing skills needed some work, that it would be best if he waited until we helped him. "I can do it," Ray said.

I thought some more about pictures on the walls. I thought about my own walls and what I choose to put on them. I thought about people who choose to leave their walls bare. I thought about art and its use in creating a warm, home-like atmosphere for people with disabilities living in their own community based homes.

While I was thinking all of these thoughts, Janet arrived to see Ray. Ray was busily destroying the wolf picture in his attempt to unframe it. Janet said, "Hey, that's a nice picture. Why are you doing that?"

It is a nice picture. Wolves are beautiful and endangered due to our menacing presence. But I don't think the wolf picture has any significance to Ray, or to Mark . I envisioned Ray and Mark 's walls with photo's of their adventures and art work of their own creation. It *would* make it more like a home and less like a motel.

Thanks, Andrew.

August 1989 –Kim Turner

Clienthood

Clients take direction from others who know better. Disabled people who rely on agencies for continuing, essential help with everyday living risk having their whole lives defined as clienthood. Options staff feel the ways that the one-down role of 24 hour a day client limits the freedom they want for the people they support. As their relationships with people grow, staff search for alternatives to the client-controller relationship.

Pushmi-Pullyu

Through the hours and days and weeks of life as a community support worker, I find myself feeling like many different things. A housekeeper, a banker, a handyperson, a lawyer, a therapist, an interior decorator. Most recently, of Dr. Doolittle fame, a pushmi-pullyu. I am intrigued with the flow of our involvement with people. How we come and go through their lives as situations change, needs arise, and issues are resolved. And I am amazed at people's ability to pull us in.

Sometimes the pull occurs with ease, and I quickly become entangled in the web of everyday life. At times I resist, pushing as they pull. I search for the middle ground as I hear pleas for assistance. What is OK? What is the right level of support which will leave us both feeling comfortable and secure? Where is the place where the challenge of independence exists without the sometimes overwhelming burden of confusion and responsibility? "Take care of me, I can't do it." "No, take care of yourself, you *can* do it, and I will stay here beside you."

Sometimes I am pushed. "Let me be, I can do this myself." Leaving me somewhat taken aback and feeling momentarily unuseful, perhaps hurt, and eventually deeply pleased and satisfied.

When I began working with Dan in the early post-reorganization days, the talk was about discontinuing Options' services with Dan. Contact was minimal. In recent months the pull has increased. Last fall problems arose with Dan and Tom, his roommate. Dan pulled, Kathy and I pushed. Eventually they resolved the problem by Tom moving out, and Dan found himself a new roommate. After several months this situation deteriorated and Dan began to pull . Dan's community began to pull also. In addition Dan had run into financial problems. He had himself convinced he could not handle a checking account, and I was over each week checking the register.

The contacts with Dan increased with the tension between him and his roommate. As it became critical we were speaking daily. Now the situation has eased, his roommate moved out and I find myself helping with bills, grocery shopping and finding a new roommate.

As the dust settles I struggle with how to begin to push. How to push Dan to be again as independent of Options as he was. Several weeks ago Dan asked me to call Dane County Housing Authority regarding adjusting his rent as he will be living alone for a few months. In a rush I said, "Sure." But when Dan called back a few hours later to check on my progress, I stopped, and said, "I think you should call, Dan."

"Can't you call?", he said, "People don't understand me on the phone."

"Sure they do. I do, and besides you are more convincing."

Dan reported in the next day, very excited. "Guess what? You were right. I called myself and it's all set." Of course it is, I thought. That was a small step, but a lifetime of "according to our records you have limited ability to do this..." and "We'll take care of you" is tough to get through. And it's a start. I'll continue to push Dan to do all he can, pull away when I'm not needed, and stand by him while he finds the space to be the competent, free-thinking person he is. Pushmi-Pullyu, Pullmi-Pushyu.

September 1990

–Maureen Quinlan

Sometimes people want to reject assistance of any kind because, for them, agency support means loss of the control they want over their own lives. When the support worker can't, in good conscience, simply withdraw, the relationship encounters a moment of truth. In such moments understanding of the relationship and of oneself can deepen.

I. Support

A few weeks ago Carol made a statement to me that I'm having a hard time understanding. She said she wanted no more help from Options. She wanted her freedom and the only way to achieve this was to not need anyone.

On one level I understood what Carol was saying. She wanted control of her life and as long as Options was involved she couldn't have it. On another level, though, I couldn't picture her life without support.

Since Carol and I talked that night I've thought of my life and all the times I needed someone and they were there. I also remember a time when I felt much like Carol. Too many people had let me down so I shut them out.

I could tell Carol stories about how my life fell apart and if it hadn't been for the support of a very special person I might still be feeling the way she does today.

For all the stories I could tell Carol, though, I'm not sure I could ever make her believe support in any way is good. My feelings are not tangible to Carol and, at the same time, hers are not tangible to me. Maybe if most of the people I'd ever known had been paid to tell me how to run my life I'd feel the same way. And perhaps, if just as I'd started to like and trust those people they'd suddenly disappear forever, I would want that kind of support even less.

II. Privacy

Last week I wrote a story about support. Today, after recopying the story, I realized it wasn't something I felt I could share. I tried to write another story that was less personal but couldn't. I was having trouble with it because of my need for privacy. Sharing who I am and how I feel has never been an easy thing for me to do. Growing up in a small town there wasn't such a thing as privacy. Everyone knew everybody's business. Somewhere along the way I decided the only way I could have a life of my own was to move to a bigger town and build walls around my family and friends.

Perhaps if I had met people who were as supportive as the people at this table I wouldn't have needed the walls. Perhaps not. In either case maybe next time it will be easier to let people in.

When I think of the people we support it's rare that I think of privacy. I remember my first weeks of working here and feeling overwhelmed with the facts of people's lives. What troubled me even more was the ease with which people shared these stories with a person they didn't even know. I kept getting the feeling that because these people had a disability their life was not their own. They had to tell all their fears, failures and successes. Maybe this is more of a problem for me than the people I support. I don't know. But I can't help but wonder how I would feel if suddenly I were in their shoes.

September 1989 –Missy Fizzell

Because support workers assist people as they deal with other human service agencies, they have opportunities to feel the experience of clienthood along side the person they support. This sharing can strengthen alliances.

Hoops, Hoops, and More Hoops

Alice and I went to [a housing agency] this week to become enlightened about their Section 8 program. Alice couldn't quite understand why they needed her for three hours and I'm afraid I

couldn't justify it to her except to say, "These are their rules and they're going to help you pay less rent, so we have to go." Being in conference room 610 with eight other people in the same predicament made me more aware of all the hoops people have to jump through in order to get something that is rightly theirs. The woman giving the orientation was clearly not thrilled with the prospect of being in that room with all of us for three hours. I could see her disapproving look when a woman walked in at 9:02 (fortunately for her it was not past 9:05 or her entrance would have been barred), with her young son in hand. The [housing agency] woman's look clearly said, "Was it absolutely necessary to bring that child here?" since the rules of the letter inviting us to gather stated in capitol letters NO CHILDREN UNLESS ABSOLUTELY NECESSARY. As the orientation commenced with each of us dutifully following along line-by-line, with no one skipping ahead or asking questions, Alice leaned over to me and said, "What is this woman talking about? You're going to have to explain this to me later." I nodded and wondered how many other people in the room felt that way as the list of don't do's and must do's blended together. "This form is for you, this form goes to the landlord, this form goes to us after the landlord signs, but before you sign it and after we sign it, after Social Security verifies it, but before HUD sees it - or was that the other way around? Hoops, hoops, and more hoops.

Fortunately for us, we were sitting in the first spot on the right and it was the first Monday of the month, and the stars were lined up in our favor, so we were the first chosen for our individual assessment of eligibility. The [housing agency] woman's tone seemed a little softer as we met 2 on 1, but I think that was only because we had all of the right forms, had successfully dotted our i's and crossed our t's and hadn't brought children. In short, we had made her job a bit easier and she didn't have to deal with us long.

Alice withstood this hoop-jumping remarkably well. She had even come to the meeting out of cigarettes, but successfully managed to bum a few from some other jumpers. She's still not sure how this is all going to work, but I'm trying to assure her that it was worth it to have her rent cut in half. After three years of being on the right lists, standing in the right lines, and filling out the right forms she can now pay only 30% of her income in rent, instead of over 60%. I don't begrudge the [housing agency] woman, she's just doing the things someone else in some big office building, somewhere has sent down. In terms of income for Alice, I guess the hoop-jumping has paid off, but it still doesn't seem quite necessary.

March 1988 –Sarah Salzwedel

Keith's Privacy

I sat with Keith at Marc's Big Boy listening to his most recent round of refusals to allow [a housing agency] to invade his privacy. What would it be this week? Anger about the long meeting, about missing work? Short notice? Not wanting any services? The inspection - right, we haven't gotten over that hurdle yet. I wondered if I would be able to talk my way over this one with Keith; to convince him that putting up with all of the [housing agency] nonsense is to his benefit. At this point, I'm fairly unconvinced myself... It's hard to be persuasive when you don't believe what you are saying.

I look up at Keith and realize he is talking to me. "Do you understand how I feel? I just don't like being pestered. That's the problem with apartment living programs. It's like Priscilla Presley, or Davy Jones and Peter Tork of the Monkees."

"What's like Priscilla and the Monkees?" I asked Keith. Keith often uses the lives of famous folks, or movie plots to help make his points, but as often as not, I haven't seen the movies, so his analogies are lost on me.

"You know —the press! Photographers and reporters hounding you, pestering you. They didn't have any privacy. Just like that inspection. I don't see why [the housing agency] has to see my

BEST COPY AVAILABLE

bedroom. Can't I have some privacy? I just want to be left alone, to be treated like everybody else. I don't need all of these services. Can't the people at [the housing agency] understand about *Privacy?!"*

"I understand what you mean Keith... it's just that you have gone through most of it already, so it won't take much more time to get through the inspection and get the rent subsidy. It will be nice for you to have your rent lowered." I say this to Keith remembering how hard it's been to get this far, and again wondering why we are doing it... they probably won't save enough money in twenty years to make all of this worth it.

"I just don't want to be pestered. I don't feel like cleaning. I'm a little under the weather you know."

"Keith, would you like a little help getting organized? I'd be happy to work on it with you next week."

"Well... if it wouldn't be too much trouble, would you come over? Are you sure you don't mind? Do you want me to fix you anything special? You probably won't have time for supper with all the cleaning that needs to be done..."

"Oh, thanks Keith, but I'm used to getting home late. I'll be OK. This way we will have more time to work. Maybe we could have supper together another day." I thought to myself - someday *after* the cleaning is done.

July 1988 –Kim Turner

Sharing time together can move a support worker beyond a staff-client relationship. Especially when the activity challenges the staff person's own competence.

Bowling with Eileen

Going bowling with Eileen - yeah, that's a great thing to do to "build a relationship", "help us connect" or "help us create a bond and build trust". Well, quite frankly, those words and terms went out the door when I saw Eileen walking out of her apartment with sports gear in hand and bowling on her mind.

To me, this meeting was supposed to be a chance for us to get to know each other better, and yes, work on building a relationship. Since most of the time we had spent together was business-oriented, or spent going to appointments, this was to be a break from that mundane stuff that would be fun and useful at the same time. Eileen on the other hand, had different ideas...

Eileen came prepared with her own bowling bag, ball, shoes, and scorecard. I could tell from the start that bowling for Eileen was a serious thing since she had a record of all her scores for the past three months (at least) tucked into the side of her bag. Eileen picked our lane -waiting patiently for me to find a ball that was usable. Eileen also took her turn first. She walked up to the lane, threw the ball, a good one - knocking down about half the pins. She tried to finish the spare, but when she didn't, had comments about what she should have done - just like all the other bowlers in the world do when they don't make a shot.

Eileen's advice continued to me - my first shots were pretty bad, but Eileen had advice about aiming for the arrows on the floor, holding the ball more on its side and releasing straight away instead of "curving it" as she said I was doing. She suggested I move to "this side more", or try to watch my steps, or something. Hearing Eileen's bowling advice, and seeing her get so involved in the game made me see a new side to Eileen. We were actually having a good time - not work time or time talking about problems, but two people going bowling in the middle of the day to get out of the heat and have some fun.

As the games progressed, Eileen's advice paid off. A couple of strikes in a row, and Eileen was calling me a "turkey" but she wasn't upset, she was giving me a hard time. Her competitive nature took over and she got some strikes and spares herself. Comments about not making a "shot like

that" before came out, but in the end it was apparent that we had fun and we both did well. Eileen immediately wrote down her scores on these games, compared them to previous games, and asked me if I wanted to look at her scores.

"I did bad on the first game, but I got 30 pins more this game. Not bad, I guess - at least I got better," Eileen said. Yes, Eileen did fine, I did fine, and we had fun. We both said it would be a good idea to do it again. Yeah, I'd like to spend another afternoon bowling with Eileen. Who knows, maybe we'll both do even better next time...

July 1989 –Theresa Fishler

Some people resist attempts to cast them in a client role. They develop the tools to define situations in their own terms.

He Calls Me His Accountant

Randi's brother started his own business a couple years ago; he cleans cars and restores them so they look like new. Randi says his brother is getting by... making good money. Randi would like to start his own business some day. Randi asks me how he could get the money to start a new business.

Randi doesn't want me to be his social worker. He despises social workers, among others, because he is their label. Randi doesn't like to be the labels of others. Randi labels them... it's a battle of labels.

[A day program] called Randi a TPR Unit 4 Level 6. He called them assholes.

Randi has a more accurate labelling tool.

George* and Randi would find each other as equally disturbing... both blame the disturbance on social service systems.

George, upon meeting Randi, would blame the liberal, do-good, social system for Randi's unsightly appearance, his cockroaches, his use of drugs, his past criminal record, his equally-as-disturbing friends... especially the one with large tattoos. George thinks that if we were really humanitarian we would better protect Randi, and improve his life, by taking care of Randi institutionally. This would also protect the community from unsightly folks.

Randi also blames the social service system for the conditions of his life... it's the system that labels him as unfit, unadult, unsmart, unmotivated, unpolite. Randi tries to break out of their label game... he does this by getting mad at them... this only earns him another label... uncooperative.

Still Randi persists, he fights the battles, he calls his senator, his alderperson, the supervisor at Social Security. He doesn't trust others to fight his battles... he will use other's positions to help him fight... but each battle is his.

George only sees the unsightly, not the dreams. Randi has dreams. He wants to be a chef. He wants to travel... maybe to Graceland or Hawaii. He wants to buy a house for he and his woman friend. He's talked about having children and family. He wants to buy... a car, a CD, a new VCR, a new stereo, furniture... the list goes on. Randi likes to buy lots of things... it's a way for him to be labelled correctly. He understands that one of the lines of the national creed is... He who hath lots is OK.

Unfortunately, Randi doesn't earn enough money for his dreams. He has to buy money at 21% compounded daily to afford his dreams.

George gets lots and lots of money for spouting his opinion. Randi, who I would guess has just as noisy opinions as George, gets no money for his opinions.

*George is a columnist who had recently written about deinstitutionalization as a misguided policy which he sees as a major cause of social disorder.

Their opinion about social services is the same… it doesn't work. George has to live next to unsightly, different people. Randi, because he's labelled, can't get his dreams.

A while back, I went to Randi's. He had some friends over. Randi wanted me to help him figure out his monthly bills. His friends asked who I was… why I was involved with Randi. Randi told them I was his accountant.

Getting back to the way to start a new business Randi… I really can't tell you how you could get some money to start a business… I really don't know.

—MORALS—

"I guess I don't make too good of an accountant." S. Nichols

"If you can't say something nice, don't say anything at all." Thumper

"Let's get out the big guns and go after those fuckers!" Randi

–Sid Nichols

Clienthood can decrease as people's ability to exchange assistance with friends and neighbors and family increases.

I'll ask my friend

"Yes, I'll stop by to get my check today," said Alyssa. "I'll ask my friend, Jim, to bring me over and then he can give me a ride to the bank."

"O.K. Alyssa, I'll see you then," I responded.

A typical beginning to my conversation with Alyssa but not the typical end. More and more lately Alyssa has stated that she will ask a friend to help her with something rather than asking someone at Options as she used to do.

Alyssa is someone who came to Options with a well developed network of friends around her. People who were not paid to be with Alyssa, who spent their free time with her and actively sought her company. But Alyssa was a person who was trained to be a client and to rely on "professionals". Little by little this has been changing. At first Alyssa was very confused by our suggestions to get a friend to go with her, to help her, etc. But I think she's beginning to see that her friends are just as good at helping her and maybe even better. Someday I expect my conversation with her may go like this:

"Gee, Alyssa, I haven't seen you in a while. How have you been?"

"I have been fine, Amy. Jaimie took me camping up north this summer and I had a great time. I got to go in a speed boat again."

"That sounds fun. What else have you been up to?"

"Well, Jim's mom died and that was sad, but now the house is his and he asked me to live with him. He can give me a ride to work every day since he goes to Madison to work, too."

"So are you still working at the Waisman Center?"

"Yes, I still work there three mornings and then go to help at St. Paul's. I also work at ARC with Donna on two afternoons. I'm making good money now."

"How is your family Alyssa?"

They're fine. I'm going over for Sunday dinner this week and Jim is coming along. My mom and dad like Jim."

"It sounds like you and Jim are getting along real well."

"Yes, he's a very good boyfriend. Sometimes we even go out for dinner now and we joined a

bowling league with some other couples. I'm not a good bowler but I get to have a beer and it's fun."

"Well, Alyssa, it was great to hear from you. Keep in touch, O.K.?"

"Sure, Amy. I'll send you an invitation to mine and Jim's housewarming party. Laurel is helping us plan it."

–Amy Lutzke

The everyday experience of prejudice tempers hopes for escaping the bonds of clienthood by simply withdrawing paid support in favor of spontaneous help from neighbors.

Making Fun

"People are making fun of me," Alex called, very upset to report that the employees at the PDQ next door to his apartment were making remarks which were hurting his feelings. They were saying things like, "Here comes dummy" and other comments which left Alex feeling confused, angry and hurt. I asked Alex if he wanted me to go with him to PDQ to talk with the manager. Alex said the manager was one of the people making the comments, and that he didn't want me to do anything about it. As far as Alex was concerned the damage was done. For the first time since his move to his new apartment in July, Alex talked again about "getting out". I could finally begin to understand what he meant by that. Alex says he needs to "get out" of places where he does not feel safe, or "at home". I found myself feeling angry and confused as well. Why would these people make such hurtful comments? What could they be thinking?

Stacy has been spending time with Rod and she told me about a conversation they had about people making fun of him. Rod said that people frequently yell things at him about his appearance, or what they judge his character to be. But he is ready for them - he has a response which is comforting to him. He says, "I was born this way. What's *your* excuse?" Rod seems to accept this as a normal part of his life.

A field instructor made her site visit to talk about a student's experiences at Options. In the course of the meeting she told a story about her visit with another student the day before at [a private institution]. She talked about her horror at being seated in a waiting room with "MRs" on either side of her. They even talked to her. She could have died! And she surely would die if she ever had to work in a place like that. There was at that moment a high likelihood that she could die in my office.

Probably most people in this room can relate to and understand the feelings that accompany these types of remarks - few people escape the experience of having strangers comment on their physical appearance, clothing, or personal characteristics. So what? A common experience that we should all ignore, right? Is that what we should tell Alex and Rod? Stacy told Rod that there are a lot of mean people out there. Is that it?

Is this something that people who are in some way different have to accept in their lives? Is it human nature? Is it ignorance? Is it fear? I suppose that it is a little of all of those things. So my next question is how can I help? What is it that I can do to help build community, or build bridges that can begin to turn around these kinds of events?

My anger and my own fear get in the way at this point. I have a long list of mini traumas of my own from similar experiences. It doesn't happen every day in Madison, but it happens often enough to keep me vigilant, scared and angry. All it takes is one person, or worse, a car full of men in an altered state to yell Dyke, Queer or other comments to send me running away from the community.

It makes it hard for me to feel OK about approaching Joe or Josephine Community to ask him or her to get to know Alex or Rod, or even me. If it doesn't feel safe to me, how can it be safe for them?

I guess the resolution to my questions has to do with risk taking. It's something I'm told I should do more of. OK. I'll start simply and in a safe place by reading this story.

March 1989 –Kim Turner

Control

As deeply as they value each person's right to live well in the home of their choice, Options staff feel a commitment to people's right to be in charge of their own lives. These values set a dilemma at the foundation of their work. A dilemma that surfaces again and around issues of control and becomes especially painful and confusing when staff see no alternative to taking charge in order to protect a person's ability to remain safely in the community.

An important part of the meaning of working at Options lies in the contrast with the imposition of control in many other human service programs.

Why I Continue to Do This Work – Part I

Contents Glass: Handle with Care

Dan grabs the log and runs
toward a large plate glass window
I dive, tackle Dan and sit on TOP.
Dan hits my face
I am commended for saving glass.

New porch door with eight panes
of glass for Ken to break,
tempting fate. I put it in context of
years in prison… tackle understanding,
panes removed replaced
with plastic, saving glass again.

Roy in arm restraints ready to receive
RESPONSIBILITY for
hitting faces
breaking glass
smell ammonia, water in face, smell ammonia
smell ammonia, water in face, smell ammonia
thank you or sequence is repeated.

Plastic tumblers, glasses break,
tossed over the shoulder of the man on TOP
tea time begins, residents
run grabbing tumblers
tap water one scoop of tea
THEY enjoy a break.

A smell is there every time the glass door
opens, passing through
man sits with pants around ankles naked
on the cold linoleum floor
no one notices the grunt. Voices
say hello from behind the glass.

I do not want to hear the voices so
THEY become the retarded the mentally ill,
otherwise voices would call me
for I might break glass,
for I might hit faces, be put away,
but not as me, as them.
I save glass.

In my dream the people did not talk
NO VOICES
just
glass
breaking
everywhere.

Why I Continue to Do this work -Part II

Behind the walls of concrete and bricks lives waste away.
Ken lived behind walls 25 years, Darwin 40, Terry 44, Bruce 38.
Many more have lived there longer, many have died there.
I know people who've been beat, left in bed, raped, arms broken, drugged, locked up, tied up, left naked in urine on the floor.
No one I know has ever asked to go back.
A place where they let Bruce's teeth rot.
A place where Ken could never talk.
A place where Darwin could never work.
Places under the monitoring of a Division called CARE AND TREATMENT.
PRISONER: a person confined or kept in custody.
INSTITUTION: a place of confinement, as a mental hospital
Hundreds of people in Wisconsin locked up behind the walls.

One by one people will leave.
One reason I continue this work is to see that more people can move out.
To go home, to meet others, to work, to have fun, to begin a new life that had been taken, been confined.

November 1990 –Sid Nichols

Social requirements, expressed in unexamined images of normalcy, can distort relationships and create the expectation of control. Increased consciousness and thoughtful decisions about when to let things be strengthen relationships.

In Our Image

I was looking forward to my visit with Christa. It had been two weeks since she returned from camp and I hadn't had a chance to talk to her about it yet. Although the idea of camp for a 32 year old woman wasn't terribly desirable to me, I supported Christa's desire to go because it was very important to her. Christa had been looking forward to attending [a summer camp for people with disabilities] for months. This year, for the first time she had some extra money and was splurging on the "luxury" of a Care Cab ride so that she could attend in her electric wheelchair. Christa saw this as a major step in her ongoing struggle to take control of her life and be independent. The ability to move freely without depending on someone else for that mobility, something most of us take for granted, is a daily struggle for Christa. This year was also special because Christa would be at camp with her best friend, Mark.

"Christa, tell me about camp," I asked as I settled myself in a chair. "You were so excited to go this year. How was it?"

"OK," she said, the disappointment already evident in her voice. "But you're not going to like it."

Christa's body tightened and flexed in her wheelchair, giving the impression that she might pop right out of it. I had come to recognize this posture as characteristic of anger or excitement. Her face, twisted with the anguish she was obviously feeling, Christa explained in a tight, high-pitched voice, "I'm supposed to be independent, but I left my camera at camp." Nearly breaking into tears, Christa went on to explain that she had reminded her counselor to pack it but she had obviously not

done so. On top of that, she had also left behind her pillow and had to borrow one from a friend when she got home.

Christa's words and the manner in which she spoke them conveyed anger at herself for somehow failing to live up to the high standards she holds for herself and fear that I would, therefore, be disappointed in her. Why wasn't Christa telling me about singing around the campfire, swimming, sunning, seeing old friends and making new ones. Why did the loss of a cheap, instamatic camera and an old pillow signify so much to Christa and overshadow everything else that had happened at camp, and why was she afraid of my reaction?

Somewhere along the line, Christa had interpreted messages about autonomy, choice, self-advocacy and independence from service providers to mean simply that she had to be perfect, like us. Because she has a severe disability she can't afford to make a mistake, to look stupid, to laugh at herself, to enjoy life, to be ***human***. Seemingly unimportant, everyday events often take on monumental significance in Christa's struggle to live in that perfect image that others had helped to create for her, in spite of the fact that she often has very little control over what happens.

In the course of this one brief conversation I suddenly felt like I knew Christa much better. I also realized that my challenge, though, was to let Christa know me better; to know my fears, my weaknesses, my mistakes. To know that mine was not a perfect image to aspire to.

July 1988 –Julie Nichols-Younes

New Boots

"Bye, Miss. Hey, Miss. I don't have to work tomorrow. Goody, Goody! Tell Rich to say hi to me."

I turn to say more to Butch but the door is already closed. We've had our weekly meeting and probably won't talk again until next week. I'll see him off and on all week as most of you probably will, walking down Johnson Street on his way to work.

This week Butch asked me the dreaded question - Would I take him shopping for new boots? I had noticed the old ones were in bad shape but every time I saw them I also saw a mental image of Butch that stopped me from bringing it up.

For years, in warm weather, Butch has been donning his shorts and wading boots, grabbing his innertube and walking around Tenney Park to "cool off". For years he has been teased and laughed at by many people for his appearance. People have asked him countless times to change. When I bring up the way he looks he says something like, "I forgot," or "I'll change before I go to the lake." Then I see him later, boots still on, making his way to Tenney.

Does Butch realize how different he looks? Probably. But does he care? Probably not. If he did, the years of trying to change him would have done so.

So I guess I'll tell Butch on Thursday we'll go shopping soon. We'll buy new boots and in late spring we'll get a new innertube. As summer approaches we'll talk about wearing tennis shoes instead of boots. I'll talk and he'll listen and that's something that probably won't ever change but that's OK because Butch probably won't either.

March 1988 –Missy Fizzell

Dealing constructively with control requires willingness to increase self knowledge.

Risk

"If you don't risk anything, you risk even more." –Erica Jong

"You must do the thing you think you cannot do." –Eleanor Roosevelt

"All glory comes from daring to begin." –Anonymous

After an erratic, confusing and sometimes scary childhood in an alcoholic family, I found myself focusing on and striving for stability, calmness, and predictability as an adult. While I always enjoyed seeing and doing new things, I needed a home base, a place where I could truly be me, and things would make sense. However, as I reflected on my life and work over these past few weeks, and the concept of risk developed in my mind as my power word, I was realizing that many of the moments in my life where I've really felt the excitement, and the meaning of the ebb and flow of life were when I took risks. Some of the outcomes are not necessarily positive or happy, but when one truly takes a risk, it generally has profound impact on her life.

A few years ago I felt uneasy with my life situation and took the risk of losing it all, and moved out on my own in search of greener pastures. That decision ended a relationship and changed my life and my perceptions of myself forever. Now I struggle with similar questions in a different situation and a different relationship and ponder the risk to go and start anew versus the risk to keep it going and work it out when I'm not sure which is the healthiest. The frightening thought of the impact this choice will have on my life at times is paralyzing.

Coming to Options to do my field placement as a student was a risk at a time when I was riddled with insecurities of my capabilities and interests. Taking that risk changed the course of my life.

I watched my brother take a giant risk to disrupt his entire life in an effort to help himself and grow, and this Thursday he will be celebrating his first full year of sobriety.

And my new sister-in-law just risked her very profitable accounting career, which she had worked hard for, to do what she really wants - teach.

Risk-taking is all around us.

I learned early on that life is unpredictable, and I cannot expect too much from people or surely I will be disappointed. To me, often, simply reaching out to someone to share a feeling, or to meet someone new is a risk. But when I take that risk, and people reach back to me, it is an awesome feeling of satisfaction and wholeness - of humanness.

The power of risk affects my work in many ways. Perhaps the most obvious is encouraging and allowing people to take risks. When I talk to people I support about the benefits of taking risks - of trying new things and meeting new people and the growth that can occur, I realize I am talking to myself as well. I feel the fear and the anxiety with them.

Risk is so much a part of our work. With each person we support, we give part of ourselves to them, and risk rejection and conflict. Even with our "needless" paperwork, we take risks that what we write and when we write it may affect someone's quality of life in terms of certain supports they may or may not receive.

I guess this work is life, and life is risky. Life is forever changing, and sometimes it's hard to keep up. Risk is powerful. The risks we take have a profound impact on our lives, but the risks we don't take can stunt us. It's scary and confusing, but it's exciting, challenging and rewarding, this work of life.

September 1989 –Maureen Quinlan

James' Wisdom

When James first heard that someone named Jonathan had applied to be his housemate, he announced that Jonathan was the one he wanted.

"But - ah - ah!" I declared. "There are others who'll be interested in the job, too."

"I want Jonathan," replied James. I had the impression this was a lesson about giving my mouth a rest.

In the next couple weeks of interviews (Peter was away on the "New Parent" plan and Sid away at TASH) I found a couple of people I liked and it was time for James to meet the candidates. Jonathan was first and the meeting did nothing to dissuade James from his resolve to have Jonathan move in.

It occurred to me that the "next time" I might just have James meet all the people applying in a bunch, thus avoiding the "instant attachment to the first one who comes along" syndrome.

I relaxed for a time when James, upon meeting the second person, announced that he wanted to live with her, too. I mistakenly understood this to mean that she was equally acceptable. What James meant, however, was that he wanted to live with both. Oh fine! This problem was multiplying. We'll have to find a mansion for James and all the people who apply for the live-in position. Sid was back and involved by this time. When we explained the "one at a time" policy, James was back to Jonathan. I had some reservations about Jonathan and really liked the other two, but I was fighting a losing battle. Sid and I called Jonathan back a few times for more interviews in which he looked quite good and we talked at length about the virtues of the other applicants with James, all to no avail. Jonathan supplanted Scott at James'. With a sense of "hope for the best" I started working with the new household. Some people win the lottery, others walk away from Vegas with pockets full of cash. I seem to win by fighting my good fortune down to the wire.

My vision for James was to hire a sensitive bouncer. This evoked a picture in my head of a large, well-scrubbed, well-mannered, quiet person. This is not exactly the image that Jonathan presents. But, except for the *large*, it's exactly what Jonathan is and add in to that patient, knowledgeable and caring and you have a small idea of the person who walked into James' life.

James gets up in the morning, brushes his teeth, showers, puts on clean clothes, goes down and makes breakfast. He helps keep the apartment spic and span, does laundry, shops for food and comes home with food.

I talk to James these days and increasingly we have conversations about solving problems he's having and he calmly tells me what's bothering him. This is the result of someone staying with it for perhaps the first time in James' life and James determination to take advantage of this opportunity.

Not only is he calmer, James is learning that he can solve problems, that he can take care of himself, perhaps even be able to put the kibosh on being victimized. He and Jonathan spend weekends doing stuff with Jonathan's, and now James', new friends. I came back today to find that James will be working again starting next week.

There's a wind in James' sails and he's trimming them down with a new sense of being able to steer his own course.

The choice of Jonathan came from a place that perhaps knows better than any of us.

April 1989

–Ellen Backus

Questions that require drawing a balance between conflicting values are particularly difficult when a person relies completely on a third party for the decision.

Us and Them

In the face of a recent respite worker crisis (i.e., another one bites the dust), I've been finding my thoughts often on Darwin and his need for in-home support. This story will concentrate on Darwin's regular, permanent, weekend and live-in workers (Randy and Jim) who also happen to be the two most important people in Darwin's life.

It's often too easy to get caught up in the problems and hassles that support people cause, rather than remember their importance and value in Darwin's life. Why do I nearly experience a stroke every time I accompany Darwin and Randy to the U.W. Rehab and have to see every piece of food and garbage on Darwin's chair from the last six months? Why are those dead leaves still piled in the corner of the living room? The plant above it hasn't seen a green leaf or sign of life for the past three months. Why is Darwin wearing a sweater that's ripped up to the elbow? What! You want a vacation? Why is a temporary fill-in worker asking for temporary fill-in? Why hasn't somebody emptied that dirty chux pail? Why is there coffee splattered over every inch of those brand new white cupboards?

But, on the other hand, why can't I consider that in every crisis situation, both Randy and Jim have been there. They've always rallied to Darwin's aid. Rather than the filthy wheelchair, why can't I reflect on the Wilderness Inquiry 2 director's statement that Randy was the best attendant they've ever had on one of their trips? (No small statement, I'm sure.) Why can't I remember Jim saying, "Gee, I really don't like the thought of working on Christmas, but the thought of Darwin with strangers on the holiday is even worse"? Why can't I appreciate it when they take the extra 45 minutes in meal preparation to allow Darwin to help clean the veggies? Why can't I understand the stress and burn out that comes from working eight days in a row?

I need to focus my attention on the loving and caring relationships that these two men foster in Darwin's life. They are his friends, his family. Don't I hear the way that Randy affectionately refers to Darwin as "Dar" and rests a gentle hand on his shoulder? And rather than getting annoyed at Darwin for pointing to Randy's picture sixteen times in five minutes, why can't I realize that Darwin really misses Randy when he's away on vacation. And why don't I recognize that smile that only Darwin can produce when Jim bounds through the door - ready to match wits with his weekend companion. And how can I resent Jim's questioning of how Darwin's money gets spent, when he's only advocating for further choice and autonomy issues?

All of these questions bring back John O'Brien's advice to our agency a few years back. He challenged us to break down those feelings of us and them. "Them" being in-home support staff. "Us" being the Options employees. We need to value "them", include "them", appreciate "them", and break down the barriers that separate the "us" from the "them". The folks in the "them" category are a hell of a lot more important to Darwin that those in the "us" category. We cannot ignore "them" or take "them" for granted. How many of "us" would be willing, for $4/hour (sleep time not included) to cook, clean, bathe, dress, grocery shop, shave, do laundry, brush teeth, plan activities, maintain equipment, wash dishes, cut toenails, make the bed, scrub out shitty underwear, and schedule the bus - and still find the time and energy to build relationships filled with affection and humor? The Jim's and the Randy's of the world may not be model employees in some ways, but for Darwin they're the best.

March 1989 –Alice Sosinsky

Deciding when to take charge and when to back away tests the support worker's understanding of the person. Sometimes deciding in terms of agency values leads to good outcomes; sometimes to more questions.

Alice Takes the Needle

Alice spent the first fifteen years of her life living with her aunt and uncle. She spent the next thirty six years in [an institution], various group homes, adult foster homes, a nursing home and [a local facility]. At age 51 she moved into her first apartment.

Alice has had a lot of things written about her. She's been reported to have "hostile, resentful and belligerent behavior". At age 21 she was reported to be "sexually acting out in the community". (I was, too, at age 21.) Psychological testing revealed Alice "lacks sensitivity to interpersonal situations and is quite limited in her ability to pick up subtle details in situations which occur around her." Personality testing "revealed a manipulative woman as well as an aggressive, socially immature, impulsive woman". At one point Alice was denied public housing for acting "as if you were intoxicated and demanding to see an apartment". And, of course, Alice was determined to exhibit "behaviors that may inhibit a person's successful integration into the community".

Although she was found to exhibit no evidence of psychosis, Alice has been receiving daily doses of thorazine "to help control tension and agitation" most of her life. Alice exhibits initial stages of tardive dyskinesia.

So that's Alice on paper and it occurs to me that, if for some reason Options is ever forced to disband, we would probably do people a service by pulling a Fawn Hall and stuffing their files in our underwear on the way out.

Any way, early last month Alice's doctor asked her to begin giving herself daily insulin injections to bring down a glucose level that put her at risk for blindness, loss of limbs, and kidney failure. The morning she was to begin treatment I met her at the doctor's office where she announced to the nurse, the doctor and myself that this was all her own damn fault. She was fat. She'd been eating junk all her life and now she had to take the needle. She watched the nurse demonstrate how to use the pen-like needle and she asked questions like, "Will this make me feel better? Will I die like that guy at [a facility where she used to live] who took insulin?" When the nurse handed her the needle she looked at me. "Here, Kathy, you do it," she said.

"I can't, Alice," I said.

Alice looked at the nurse. "You do it," she said.

"You can do it, Alice," the nurse replied. Alice administered the shot to herself.

That night she called me. "Will you be here tomorrow morning when that nurse comes?"

"Yep. I'll be there," I said.

"Don't leave that needle in here. I don't want it in my apartment."

"OK," I said.

"I just want to die. My mother's dead. I just want to go with her."

The next morning when I arrived at Alice's apartment, the visiting nurse was filling out forms and Alice was sitting in her rocker in her nightgown. This time the nurse administered her shot, then said Alice should eat something. I reached on top of the refrigerator for a banana.

"What are you doing?" she asked.

"Getting you something to eat," I explained.

"I'm in charge here," Alice stated. "I'll get my own food!"

Day four the nurse called to report Alice's blood pressure was very high. Alice called to say her legs were black and blue and sore and she didn't need this damn insulin. "We're all going to die anyway," she said.

Day seven we were back in the doctor's office for a follow-up on the week's activities and yet another blood test. Alice said she was sick of doctors and sick of needles. But she also reported she'd bought some seven layer salad and some wheat bread and were those good to eat?

So what about all that stuff written about Alice? Does Alice talk loudly? Yep. Is she hostile, belligerent, resentful? If she chose to be, she'd have good reason, but no, I don't think so. Does she lack sensitivity, perception? Definitely not. Is she aggressive? Oh, yes, she sure is. And I would guess that that aggressiveness is the same stuff that assists her in facing her fears and overcoming them.

And I would guess that aggressiveness served her well in surviving 36 years of institutions and mini-institutions with her spirit intact.

March 1989 –Kathy Lemke

Making Things Perfect

When I came in this morning Becky was waiting for me. "Do you have anything for me to do?" she asked. "I've got nothing to do and no place to go."

Becky was a point of light, a cause for celebration when I first met her. She applied for a live-in position at a time when Peter's walls were papered with blue sheets and I was running ragged trying to keep Alice out of the nursing home and in her own apartment.

At the staffing before Alice's release from the hospital we all took our turn. Alice's medical doctor listed necessary treatment upon her release. Alice's psychiatrist rattled off labels and jargon that made me bristle with indignation. Alice's hospital social worker talked about [two nursing homes] as possible placements. Sarah and I talked about Alice, her past living situations, her fears and her preferences. I boldly said we will move Alice into a two bedroom apartment. We will hire an attendant. We will have this all in place by the beginning of next month. We will make things perfect.

Becky moved in with Alice, as promised, on July 1. Alice had been moved into a two bedroom apartment, freshly painted, next to a little shopping mall, close to the bus stop. All aspects of my plan in place, perfect. Alice had met Becky prior to the move. They liked each other. It was the makings of a story. Options adjusts services as people's needs change. Options maintains Alice's right to live in the community.

Given all this perfection, I am besieged with questions. Why has Alice been screaming at Becky for ten days? Is it my fault that Becky is sitting in my office crying under the pressure of being verbally abused and insulted? What is Alice afraid of? Who owns this situation? Do I enable Alice to be outrageous by being the one who makes her decisions for her? Did Alice choose to live with a roommate or did I choose it for her? Could I have prepared Alice better for what it means to share living space with another person? Does my need to do my job perfectly, my need to be super social worker, make it difficult for me to give up control? Behavior is a form of communication. When did I stop listening? When did I decide I know best? When did I absolve Alice of responsibility for her own life and take control away from her? Where did I get the idea that I could create another person's perfection?

"The human ego is stronger than the cockroach." "The road to hell is paved with good intentions" and the waters are murky when we try to act on our beliefs. Was I talking empowerment and acting control?

July 1989 –Kathy Lemke

Decisions to take control are painful and often frightening to implement. And, for some people, recurring struggles over control come along with the commitment to stick with people for as long as they need help to maintain their place in community. Issues can remain settled for months and then return to test relationships again.

California Dreamin' or I'm Getting My Act Together and Taking It on the Road...

It was 4:15 on the Wednesday before Christmas, Julie, Missy and I were planning with a lot of dread a 4:30 "at risk" meeting with Carol. Things were starting to go downhill for Carol and there were numerous disaster reports about the condition of her apartment, her nutrition, her personal hygiene and out of control spending habits. The purpose of the meeting was to set down some limits and rules that Carol would need to follow. Given her fierce dislike of being told what to do and her famous temper, there was good reason for our lack of enthusiasm.

We spent a good ten minutes positioning ourselves at the conference table so that we would be out of range in case Carol would actualize her anger by taking a swing at one of us. I had the dubious honor of being the one to lay down the law to Carol. My strategy was to disarm her by talking about the positive changes I've seen in the seven years that I've known her, how far she'd come, etc. As I did this, she didn't seem particularly impressed by my rap and sat there impassively waiting for the punch line. So I went on about our concerns that she may lose her independence and her apartment if things didn't change. Being the astute person she is, Carol had many specific questions about how and who could take it all away from her. I came back with my typical response of blaming it on the county.

Then I started in on the new expectations (I had a list of eight or so), the first being our getting involved in grocery shopping. My strategy was to give her two alternatives - either having staff shop with her or to check her refrigerator once a week - so that she would have some choice over *how* we controlled her life. Carol didn't fall for it. Her eyes started flashing, she sat up in her chair and suddenly her hands crashed on the table. The three of us on the other side jumped six inches off our chairs. Then she started in shouting at us, "You have no right to tell me what to do! It's none of your goddamn business what I eat! I'm independent. I don't want you interfering in my life! You say you're different but you're no better than the staff at the group homes (a low blow). I'm sick of people all my life telling me what to do!"

After she wound down we sat in silence for a while and I repeated that she had a choice but it had to be one or the other. The hands slammed on the table again and out poured more anger. I sat there feeling how much I absolutely hated being in the position of power over someone else's life. It's beyond me to think that some people actually derive satisfaction from being in that role. We went through about four rounds and finally Carol said, "What if I say `no'?" I said, "Well, you can choose not to get services from Options and try to do it on your own," knowing full well there was no way she could do it without help. She considered the idea for a moment and exclaimed, "O.K. I'll get rid of Options and do it on my own!" Her eyes began flashing again and her face lit up. We braced ourselves for the next crash on the table, but instead Carol's face broke into the biggest smile you could imagine. "I know what I'll do. I'll move to California. I'll just get on a train and move to California where nobody knows me and nobody will tell me what to do anymore. And you all can just go to hell!" This was followed by a burst of laughter that filled the room. Carol's laugh is something to behold. Like her anger it has an intensity that envelopes you and she expresses it with her entire body and soul. She laughed and laughed, head thrown back and arms waving, delighting in the vision of freedom from staff. In seconds the three of us were laughing with her - first because it's impossible *not* to laugh with Carol and second, out of relief that the anger had subsided. We all enjoyed the dream together for a few moments, Carol knowing better than any of us how unlikely it was to come true.

All that evening Carol was on my mind. I thought about how much I loved her fierce spirit, how much she's taught me about strength, survival and self determination. A black woman, labelled

mentally retarded, born in a mental institution, living her life in dozens of institutions and facilities, persevering until she got what she wanted - her own home. It's a modern day liberation story which she tells with a powerful eloquence. I wondered about her grandmother, her great-grandmother and the generations that produced her fighting spirit. I wished that Carol *could* go to California and finally be really free from all of us who still controlled her in some way. If there *was* a way, I'd gladly buy the train ticket and be there to wish her "bon voyage".

1989 –Gail Jacob

Armistice

For over a year now I've resisted a recurrent urge to write a story about Carol and her ongoing struggle with a mental illness and with defining Options' role in her life. I've often thought there was an important message in Carol's story, but I could never find a way to express it, probably because it was not yet complete. Looking back, it now seems as though Carol and I have come full circle, in many ways we are back to the place we started. Yet, in others, we are light years away.

The past two years of struggle and conflict could have looked to an outsider like a battle of wills to determine who would have ultimate control over Carol's life. I have to admit that in times of frustration and despair over Carol's situation, I often felt like Carol's adversary in a war of wills that I was destined to lose. But now it looks for all practical purposes like I have won. I have Carol's monthly benefit checks sent to me at the office. Options' staff are now co-signers on Carol's bank account. I accompany Carol to the grocery store every Monday, not for the purposes of training, but to be sure she buys what I consider to be nutritious food. Every Wednesday I meet Carol at her apartment to sign spending checks, contingent on her apartment first passing "inspection", and once a month I escort her to a psychiatrist's office to obtain a prolixin shot. Yes, the battle is over, but did I win? No, I don't think so. I don't think I was ever really a combatant in the war. Carol's struggle was really an internal one. Her need for independence and autonomy was battling it out with her need for structure and support from Options. Carol was unable to see that she could only have independence and "be her own boss" in her words with certain supports and assistance from us. The more control that Options relinquished, the more out of control Carol became.

She went for months without bathing. I'm sure many of you remember the lingering olfactory evidence of Carol's visits to the office during those times. She rarely changed or washed her clothes, appearing in the same menstrual bloodstained outfit week after week. Her diet consisted primarily of Oreos, Coke, and M&Ms since she preferred to spend her grocery money on dolls and toys rather than food. She was noticeably losing weight. Carol never cleaned her apartment or took out the garbage, letting garbage and spills pile up on the living room and kitchen floors. For some reason she preferred living with the stench of her own feces rather than simply flushing the toilet. She broke every agreement and promise she made with Options' staff to change her ways, insisting she didn't need our support. Usually she managed to avoid us by running away or locking us out. She begged us to let her be her own boss and to terminate her from Options. This was not, however, the quality of life of a person in control of her own life, yet for many months I resisted making a drastic move. What about autonomy and choice, what about Carol's wishes? She seemed so tormented by our involvement in her life. Finally, in spite of my guilt, I took possession of Carol's benefit checks and backed her into a corner. She very quickly and quietly went along with the rest of my demands.

Strangely, Carol seems very at ease and comfortable with our new arrangement. She has not uttered a single word of protest or dissatisfaction with my renewed involvement in her life. In fact, she seems more at peace with herself and her life than I've seen in several years. It's as if she is relieved that someone finally rescued her from the chaos that her life had become and that she was helpless to change. The guilt I feel now is for failing to end her misery sooner by working out a truce in Carol's private war.

November 1989 –Julie Nichols-Younes

Doing the Right Thing

Yesterday I don't think Leslie liked her job very well. She had to do something that she knew would hurt someone. She had to remove Mike from his home, against the wishes of his foster sponsor and without his consent. His foster sponsor, was very hurt, Mike was upset and Leslie too felt pain.

Yesterday Alice also had to do something that she knew would hurt someone. She had to give Wanda the medication that she desperately does not want to take. The side effects of the medication hurt Wanda and cause her pain. Seeing Wanda so miserable and upset about taking the pills distresses Alice too.

Both Alice and Leslie, for reasons more complicated than I've explained, chose yesterday to take control, to make a decision which was not necessarily concurrent with the wishes of the person they support and it hurt. Well, it should hurt. It should hurt like hell. It should never feel good or comfortable to take control, to wield power, to make decisions for another person. It is a decision that should be fraught with anguish, doubt, second thoughts and pain. It should hurt.

Yesterday I found myself an observer to these events. I think Alice and Leslie both did the right thing. I felt their pain, I've been there too, as have many of you. For them, these were not split-second decisions taken lightly. Both have struggled for months to decide what was the best thing to do for Mike and Wanda. Sometimes the right thing to do is the most painful. In fact, sometimes if it doesn't hurt, it's not the right thing to do at all.

December 1989 –Julie Nichols-Younes

Out of Control

Control. I'm not sure if I've ever known anyone who did not identify for themselves that they struggle with how to be in control and have power without overdoing it. It's quite a fine art, it seems. Many of the people Options supports seem to be actively trying to work out their own control thing. In the process, that much sought after middle ground is sometimes zoomed past to a point of no control in the name of personal choice.

Sandy's life is out of control. It is very clear to everyone who knows her, including Sandy herself. Unfortunately the struggle to have, and be in control, continues to propel Sandy even further out of control. It has to stop eventually, but there is no end to it in sight.

Sandy says that she needs people to be "strong" with her, and that if she had male attendants, or lived in a group home, everything would be OK. Her attendants, who have attempted to help Sandy set limits and regain some control have become the subject of relentless abuse. Sandy is using her need for personal care assistance to hurt her attendants. Physically and emotionally, they are unable to cope. They shouldn't have to stay in a situation which is so abusive, but what else can they do? What else can we do?

Symptoms can be managed, but how do we get to the heart of it; how do we identify and correct the underlying problem? There is a scary similarity for me to the struggles our team has been going through as of late. The team members, kind of like attendants to the Team, reached a point where we could no longer physically or emotionally cope with what began to feel like abuse from a struggle for control. It was clear nobody could win, much like Sandy's situation.

The team issue is at least temporarily resolving itself by finding a "respite" situation for one of the team members. If I think about Sandy's connection to, and need for attendants as a team, it is clear Sandy is the team member with the need for a break, for respite, for change.

My questions are 1) what should we stop doing which is enabling Sandy's current out-of-control behavior, 2) what should we start doing to enable her to gain real control of her life? Our team

needed to reach a point of crisis before the changes could happen. Sandy's life seems to be in crisis, but I am not sure it has reached its high (or is it low) point.

Gail and I talked about the alternatives available for a temporary alternative placement for Sandy. I noted with some irony and sadness that Sandy is the third person in about as many months that I've felt the need to seek a more restrictive temporary "home" , i.e., placement for.

The problem with thinking about it is how to give people the structure and controls they need and are unable to provide for themselves, but still empower their personal growth. The alternatives available (if they *are* actually available) seem to do nothing to help with that growth. At best, they are custodial. At worst, they are prisons.

My reflections on this dilemma have led me to the conclusion that what we need is...

I let this story sit unfinished for a few days, hoping I would become more enlightened. I'm still waiting to find the answers. I was even hopeful I could reach a humorous, if somewhat outrageous conclusion. That didn't happen either.

August 1990 –Kim Turner

Suffering & Death

Long term, close involvement with people confronts support workers with the reality of suffering and death.

Feeling powerless to relieve someone's obvious pain challenges the meaning of one's work.

Hell on Earth

Saturday morning the phone rang jolting me out of a deep sleep. I reached for it and registered the time on my digital clock: 5:12 a.m. "Hello, this is Carol. Those neighbors are bothering me again, yelling through the wall, calling me a faker..." the now familiar litany of complaints flowed on in Carol's rapid-fire monotone. "Carol," I interrupted, "it's 5 in the morning, I'm sleeping, call me back after 9:00." After squeezing in two more examples of the neighbor's injustices, she mercifully signed off.

The voices in her mind have been taking over her world, shrinking it now to the space of her living room. The plan had been to petition the court to place Carol involuntarily into a hospital for a psychiatric evaluation. All week on my vacation, the image of Carol being hauled away from her home by police haunted me. Obviously it hadn't happened.

The phone rings again, 6:45 a.m. "Hello, this is Carol. Those neighbors are making noises just to tease me." "Carol, I know you feel bad, but I'm too tired to talk to you. I'm still sleeping. Call me later, after 9." The calls kept coming all day and into the night.

This morning, another call... "Those neighbors are bothering me again, every time I blink my eyes that man starts teasing me again..." I tried the reality approach. "Your neighbor works during the day, there's only a woman living there." And Carol was off in a rage, "You think I'm lying, you don't believe me, you're the one that's crazy!" I changed the subject. "You're being evicted, what are you going to do about another place to live?" Another tirade, "I'm not leaving, no one can make me." We argued back and forth. "Carol, you might end up in a homeless shelter, because who is going to rent to you when you're like this?" "You've got to be out of your mind, woman. I'm not going to no homeless shelter. The whole world is coming to an end. The world is coming to an end today." Carol," I asked. "What do you mean?" "Oh, I just said that to get you going. If you're going to talk crazy, I can too!" And the worst insult yet, "And I'm *not* inviting you to my birthday party this year!" (I'd been dis-invited and invited many times in the past few weeks.)

A long pause... "You know, this is hell on earth, right here... this is hell on earth."

"I know Carol, I know it's hell for you. I wish I could help you, I wish there was something I could do to help."

August 1988 —Gail Jacob

Just Say No

This is a story of a friend of mine, a brave woman who has been fighting a battle for many months now. The battle isn't with enemy countries or terrorists but with her own mind and with a mental health system which is primarily designed to serve itself.

The battle began last summer when Nancy, normally an energetic, happy-go-lucky sort began to spend days at home crying for no apparent reason. Though she returned to her former therapist to see if they could work out the cause of her sadness, Nancy began to feel even worse. The depression progressed to anxiety and fear of things that were previously enjoyed. Frightened to ride the city bus, Nancy was unable to seek out her friends, go to work, to the community center, or to her volunteer job at St. Paul's.

Though Nancy had always been adamant about not wanting to take any medication the people involved in Nancy's life began to feel this was an option that warranted consideration.

When a psychiatrist's evaluation confirmed that Nancy was truly depressed she recommended hospitalization in the _____ to begin anti-depressant medication. This was described as a relatively brief stay to begin the meds and monitor any immediate side effects. When her therapist and I explained this to Nancy, much to our surprise she readily agreed. Unfortunately, she had to wait another week to be admitted.

When I arrived on the day she was to go to the hospital I was sure Nancy would refuse to go. Again, I was to be surprised when she met me at the door, packed suitcase in hand. It was at that moment that I began to understand Nancy's desperation to feel better.

Well, Nancy's brief stay to begin anti-depressant medication stretched on to three weeks. The _____ staff were compelled to do their own evaluations, all of which were arranged, of course, at the convenience of the physicians involved. For the first week Nancy packed her suitcase each day and announced her intention to leave when someone arrived to visit her. Reminding her that she was not being kept there and that she could leave whenever she wanted was all that it took for the suitcase to be unpacked again.

Staff at the hospital who knew what was the plan for Nancy were difficult to find. When requests for a staffing were made the answer was always that it would happen any day now. Nancy was there for ten days before it did.

I'll never forget the sinking feeling the day I called Nancy and she announced that she had just received a shot of Prolixin. When a frantic search through the PDR revealed that this was an antipsychotic, I, too, began to feel truly depressed. What were they doing to Nancy?

At the staffing, when it finally occurred, total strangers pretended to know what was best for Nancy. These things included Haldol to treat her Tourette's syndrome and her new diagnosis of psychotic depression, a possible anti-depressant to go with that and an AIDS test. Choking back my growing sense of righteous indignation I questioned their diagnosis, their decision to administer Haldol, and their concern about AIDS, reminding them that we already knew Nancy had Tourette's and that was not why she was there.

Nancy left the hospital ten days later with a prescription for injections and for an anti-depressant called Prozac. Her Tourette's tics had stopped and though she still felt occasionally weepy her fear and anxiety about things had subsided. Though I still wondered about the benefits of replacing Tourette's tics with tardive dyskinesia, I wondered if perhaps I had judged the _____ staff a bit harshly.

Unable to find a reliable psychiatrist who would bill MA and could take on a new patient, Nancy was able to continue working with her primary psychiatrist from the _____. It took them about six weeks to work out an acceptable Haldol injection schedule. That was about the time Nancy's hand began to shake uncontrollably and her right eye turned inward.

We were out for coffee one day and as I watched Nancy struggle to take a sip of coffee without shaking the whole cup into her lap, I asked her which was better, the jerks from her Tourette's or the shaking hand. A little taken aback at my request to choose one of these conditions, Nancy looked me in the eye and said, "They are both bad."

This began Nancy's search for an antidote for the side effects from the Haldol. She had pretty much stopped taking the Prozac and as the crying had subsided we dropped the anti-depressant for now. First she started with Cogentin. The shaking had gotten a little better but now Nancy had problems with her bladder. She had complained off and on since starting the medication of pain in her abdomen. She was now experiencing urgency and frequent urination. The psychiatrist made a referral to a urologist - also at _____ hospital.

The day Nancy and I went to the appointment she was experiencing a lot of discomfort and was feeling pretty anxious. She had been to the bathroom three times in twenty minutes when we were

called into the examining room. A nice intern came in and took information from us. He seemed compassionate and concerned. It sounded to him like the problem could be the result of Nancy's meds, all of which were known to cause urinary retention. When he left to get the guy they call doctor, Nancy excused herself to use the restroom one more time. When the doctor and intern returned Nancy announced that she would prefer not to have an exam. Doctor looked at her benevolently and assured her there would be no reason for the exam. He asked her a couple questions and confirmed that she had been referred to him by a psychiatrist. He then began to talk to her about people who are very anxious and hurry when they urinate. He said that if they took their time and relaxed that their problem went away. He then patted her knee, stood up and looked at me. "Is that OK?" he asked as he moved toward the door. My brain said, "Is that OK? What the hell is going on here? Do you think she is making this up? What about all the damn drugs she's taking?!" But my mouth said, "Sure." Nancy and I left the intern with his mouth hanging open in disbelief. Nancy took this guy's diagnosis in stride, not feeling insulted by his obvious insinuations at all. I decided that if a urologist was necessary - this was not the one.

About this time Nancy also began taking Amantadine to continue to try to reduce the side effects of the Haldol. They were a little better but then Nancy became very sick. Her psychiatrist sent her to the emergency room on Tuesday because she had been vomiting for a few days and her G/P was unavailable. They did some tests, diagnosed the flu, told her to go home, rest, and stop taking the Amantadine. Four days later she was still throwing up. Three trips to the emergency room later Nancy was finally admitted to the hospital and put on an IV. She had lost more than ten pounds and could hardly talk she was so weak. They tested her for AIDS and hepatitis. The tests came back negative and she came back home.

Since then Nancy has tried Artane and Kemadrin to stop the shaking hand. Neither has been very successful. In addition, she continues to have some stomach problems for which she now takes Zantac which is used to treat ulcers.

A few weeks ago Nancy began to talk about feeling sad again. She explained that she had sometimes found herself crying, again for no apparent reason.

Nancy's psychiatrist also left to have her baby so Nancy is just getting started with someone new. So far this doctor's response to Nancy's concern about feeling sad was to advise her to get out and do things. Nancy is also wondering about how much longer she should take the Haldol - a reasonable question I would say.

I guess the point of this story is this: one year, ten drugs and two hospitalizations later Nancy is still sad. She is going to work and seeing friends again, but she is also immersed in such a mishmash of pharmacology that it is now hard to tell what is Nancy and what is not. Where do we go from here? Do we continue to play the medication roulette, or is it time for a drug holiday? I guess I really don't know the answers but I do know that we'll keep trying to figure it out for just as long as it takes. It doesn't seem like Nancy is anywhere near ready to give up and so we had better not be either.

August 1989 –Amy Lutzke

The sense of losing touch with someone whose life has changed for the worse causes sadness and questioning.

Visiting Wanda's Mother's Grave

Last May Wanda, Alice and I made the annual trek to visit the grave site of Wanda's mother. Wanda, as usual, was talking non-stop on the way as we traveled through the Wisconsin countryside, and snapping photos of every cow along the way. Alice and I smile at each other in the rear view mirror, acknowledging it will be a long day with Wanda.

As we approach the cemetery Wanda says, "Oh, Gawd, I don't want to be buried in no cow pasture." The cemetery is flanked with farms and fields with cows grazing. We enter the cemetery driveway, park, Wanda gets out and proceeds. "Oh, Gawd, it ain't right to have no headstone." The grave site has an aluminum marker to designate the spot where Wanda's mother is buried. Wanda talks often of buying a proper headstone for the grave.

There is a certain amount of ceremony which must be performed during these visits to the cemetery. For example, Wanda brings plastic flowers and a rosary each year to the grave. There is the ritual of Alice placing the flowers neatly by the marker. And then, Wanda takes a little quiet time to herself to lie on the grave and have a private chat with her mother. The only problem is getting Wanda off the ground again. Alice and I pull and tug, as Wanda moans and groans, "Oh Jesus, Oh Gawd." The past two years the "grave tender", as Wanda calls him, has offered his help.

The "grave tender", a kindly looking man, has much to say about the business of tending to the graves. "I don't want to start trimming around the stones yet because Memorial Day's comin' up and it's a big day here. If I do it now I'll just have to do it again in a few weeks. Trimming. The dead don't care, it's for the living. He asks me, "Are you her daughter? I remember her from last year."

This visit to the cemetery is the Wanda of May, the Wanda I know best. She is generous, proud, regards herself as beautiful, an incessant talker, names most people her family, commanding, combative, strong willed, determined, and a dime store fan. But since June there is a Wanda I can't touch. Wanda, who loves to talk, is quiet, mumbles and whispers if she talks at all. Wanda, who is commanding and combative, is passive, indecisive, and confused. Wanda, who is generous, is fearful and distrusting of giving.

I miss you Wanda. I miss you yelling at me, telling me to be quiet because you have something more important to say, commanding me to do things. I feel frustrated, inadequate and tired - that I do not know how to communicate with you and gain your confidence.

It's been a long five months. I hope you regain your fighting spirit. I hope you begin to enjoy your old pleasures with the same passion you once did and I hope you begin to feel secure in the world you see around you.

November 1989 –Kathryn Mazack

Coming at This Through the Back Door

Driving along John Nolen Drive last Sunday morning, from out of the blue, a question entered my mind. "I've done this work for awhile, why do I keep doing it?" At the moment I couldn't think of anything that I'd rather do *less* on this blustery morning. But there I was, heading into this work once again. Why? A disturbing question after working at Options for 8 years, 4 days, and 37 minutes. Why?

I was on my way over to Wanda's house. Her life over the past year and a half has been filled with pain and misery. So much has changed. The problems and issues seem endless. I think it is especially troubling to me as I can so vividly remember who Wanda used to be and what her life was like.

Autonomy, choice and independence are common values and themes at Options. These things were always of the utmost importance to Wanda, too... before. Wanda was most clear on what she wanted and was the most assertive woman I'd ever met. Today, it is a daily struggle. Making choices and taking control over her life are things that Wanda finds impossible to do. Instead, helplessness and dependency continue to grow, and we're forced to make the decisions, take the control.

Personal space is another difficult area to ponder. Options puts great value on helping people make good spaces and places for themselves - both in a home and out in the community. I remember when Wanda moved into her first apartment on East Johnson Street on Halloween night several

years ago. That was her pad. She made friends with the neighbors and visited the local store. She loved that place. It was her first own real space. Now, after moving three times in a year and a half, Wanda is angry, afraid, and lonely. Unable to cope with the "problems" that neighbors cause (i.e., walking upstairs, saying hello in the hallway, stealing her yellow socks out of the dryer), Wanda sees those around her as enemies. She seldom ventures out of the apartment that she has grown to detest since day one.

Wanda's "pride and joy" used to be eating. Now she eats only when, quite literally, she's forced to. And she used to love to cash her $45.00 check every Monday - and come home exhausted after a big day of shopping, broke. Money has become one of Wanda's many "obsessions" as of late - a steadfast refusal to spend a cent. She had many friends and acquaintances down on the square that she spoke of often. She used to visit her best friend, Ed, at his home at least once a week. Now Wanda feels taken advantage of - and that her friends are stealing her money. Her beloved Ed is in a nursing home in Verona. The relationship that I felt so strongly has changed as well. I feel more like her mother, her nurse, an enforcer, another enemy.

Working at Options has always felt right to me. It made sense. Working with Wanda over the past one and a half years hasn't felt very good - and it certainly hasn't made much sense. The values and quality of life that Options values seem so remote from Wanda's personal hell.

In rereading this story, I still ask "Why?" It probably isn't clear to anyone listening - as it isn't for me either. It somehow did when I sat down to write this story. It's a very painful and perplexing question. Something would be wrong if I didn't feel this way wouldn't it?

November 1990 –Alice Sosinsky

Sticking with people life long means having to deal with their deaths.

Memorial Letter to Eileen

Dear Eileen,

I've been thinking a lot about you and our times together these last five years. The two things that really stand out about you are your sense of compassion for people who are in pain or just down on their luck and your terrific sense of humor.

We always managed to have fun in between taking care of business. I would often come to see you with a plan of things we had to do. You would often meet me at the door with your own plan. Like the time I came over with my "plan" and your favorite show `Perry Mason' had just started. So, I tucked my "plan" in my purse for another day and we watched not only `Perry Mason' but the `Partridge Family' too. It was fun laughing at the styles and talking about whatever happened to quality television like the `Partridge Family'.

Remember the time we needed a part for your blender? It was an old blender and the part we needed would have to be found in a second hand store. So off to Goodwill we went. Unsuccessful there, we went to the Buy and Sell shop. Your opinion of that store, well it's unprintable, but I wholeheartedly agreed with you. Needless to say we didn't have any luck there either. So I took you home. I pulled up in front of your apartment. You looked out the window and said, "What dump is this?"

"It's your apartment."

"Oh," you laughed. "What a winner."

You always liked to tell funny stories about yourself. I think the one about your parakeet was your favorite because you always seemed to enjoy yourself so much when you told it. And you told it a lot! When you were living in Chicago you had a parakeet. Someone let it out of its cage without your knowing about it. You were doing the dishes. You picked up what you thought was the dish rag out of your dishwater, you wrung it out and started to wipe the table with it. All of a sudden

you realized it wasn't a dishrag, it was your parakeet. I'm sure when that happened it was awful for you, but evidently you got over it because you sure had fun telling about it.

This past year, due to the car accident you were involved in, you and I spent a lot of time meeting with your lawyer, whom you referred to as Perry Mason. At the end of a very long year we were finally able to meet with a judge. He was going to decide whether you should get the money you were seeking or if your case should go to trial. He met with both of us first, then sent us off to a room while he talked with the lawyers. The room he sent us to was a small staff lounge. It was messy, had no windows, and was not air conditioned. This was in July. We waited for an hour. We talked about a lot of different things. I told you my 103 year old Grandmother had just passed away. You said you were sorry and started to cry. We sat in that small stuffy room and consoled each other. I was deeply touched by your compassion. Then the judge called us in. He told you he was was going to award you the money and that there would be no trial. You and I had a six block walk back to your apartment. I don't think it hit either one of us until we were almost home. Then I turned to you and said, "You won. It's all over." We walked home that last block with our arms around each other celebrating in the moment.

About a month ago you and I went bowling. I did OK the first game. But the second game was a trial for your patience I'm sure. I started off with a couple of gutter balls. You offered me some pointers on where to stand, where to look, and how to swing my arm. I threw another gutter ball and you suggested I use your ball. Since your ball is twice as heavy as what I'm used to I threw a gutter ball almost throwing my arm out of joint in the process. Then you suggested we find another ball. After a ten minute search for the perfect ball we found one. I actually managed to hit three pins. Then I threw another gutter ball. Finally in desperation you took off your wrist guard and gave it to me to use. After my ninth gutter ball you said, "Well, I really don't know what's wrong with you."

After five years together I could go on and on. But, as you would say, it's time to "put a sock in it". Our times together may be over, but I have a lot of memories and you'll be in my heart for a long, long time.

Good by, Eileen

Love,

Diane

November 1989

–Diane Steele

Looking at Life Through the Eyes of Death

After the funeral we drove to Milwaukee to bury Alice and to meet her aunts, Grace and Gert. Although Grace and Gert were famous through Alice's stories I had never met them or spoken to them until she died. I was to learn Grace, along with her husband Bill, had purchased a plot for Alice in a grouping of graves that included them as well as Gert and Helen, "the crazy aunt," Alice, was buried with her family.

Standing around Alice's coffin at the cemetery I listened to Grace and Gert tell a little more of Alice's story. Alice, it turned out, had a brother that was older than her. As Grace put it, "Dickey was born normal." After Alice's parents divorced, her mother Ruth, wanted to "adopt the children out". When they had examinations for the adoption, Alice "passed the physical beautifully but she flunked the mental". Grace agreed to take Alice if Ruth would promise to keep Dickey. Ruth broke her promise and no one knows what happened to Dickey. Alice lived with Grace and Bill from the time she was three until she was sixteen. "Then her mother put her in a mental institution," Grace explained. Alice was to live with Grace and Bill once more briefly when she was in her early twenties before returning to [the institution].

"No one told me she was sick," said Gert.

"I got cards from her but she never mentioned anything about it. Was she on any medications?"

"Did she get the $10 I sent her for her birthday?"

"Is Options the name of the home she lived in?"

"She always wanted her own apartment." Alice had lived in her own apartment the last five years of her life. She was 57 when she died.

Both Grace and Gert wanted to know how Alice died.

"She died at home while watching television," I explained. She'd seen two people that day, a social worker and a neighbor."

"But she died alone?" Grace asked.

"Yes."

Alice was one of my greatest teachers and after she died she was still teaching me, challenging me to look at life from her perspective. At first I couldn't touch anything in her apartment. I couldn't have the phone disconnected or the electricity shut off. Several times I went there to sit and smoke. Alice was very habitual in her life style. Her belongings were laid out in preparation for living. The clothes she'd chosen to wear the next day were draped over her chair. Her checkbook lay ready with her signature on the next spending check to be written. Her next meal was laid out on her kitchen counter. ("Alice, it's not good to have that meat sitting out all day on the counter.") A basket of clean laundry to be folded, a basket of dirty laundry to be washed sat next to the door.

I looked through her drawers for further evidence of life. I felt like I was getting away with something. Alice always yelled at me when I touched her things. Now I could look at my leisure.

The only things I removed at first were things that could be given to other people, things that spoke of life continued. Food for Barb and Tom, clothes for Barb, pictures for Sarah and Ellen and me. The insulin stuff for Carol. Matches and perfume samples and the bird feeder. To do more was to accept that it was over.

Then at some point the reality of ending set in and life looked very different to me, fragile and frightening. The stuff we the living busy ourselves with seemed ludicrous, at best, stupid, insignificant, without value, activity to drown in, to keep us from seeing how little of it really matters. Alice's money, a topic of great debate while she lived, had, after her death, no value. The pages and pages of paper scribbled with her computations for how to dispense her meager funds each month seemed pathetic. Her bills, her reputation as a tenant, her position in society, her dirty laundry, her clean laundry, her $80 in the bank, the places she could go, the places she'd been kicked out of, the hidden candy bars, the shoes she couldn't afford to buy, the batteries for her radio, the calendar that read "Bless This House". The bath mat we never bought, the purse that didn't zip right, the meds she took, the meds she didn't take, none of it mattered, not to Alice anyway, not anymore. What had been valuable with her life, was worthless with her death. And to me it all screamed of pain, deprivation and poverty. Alice was out of it. She didn't have to struggle anymore. Her battle was over. But the rest of us were still doing it. What to make for dinner, getting Meg to basketball practice on time, a borrowed book not returned, the need for a smoke-free environment (How about a pain-free environment, a poverty-free environment? Was there some director that could make that happen?), a form to fill out, angry words, vacation plans, clean laundry, dirty laundry, stupid, ludicrous, frightening, fragile. I was stopped. I was out of balance. In her death Alice was challenging me to look at the bigger picture. She was forcing me to look at our true insignificance. I knew the view would need to blur again in order for me to be able to function, to continue, but I hoped in looking at it, if only briefly, I would be able to learn better what to put energy into and what to let go of. I would always be in some way a different human being for having known Alice.

The last time I went to Alice's apartment it was to throw everything away. Throughout this whole experience I was awed by how alone she really was and how little she had. She would have been

furious to see us hauling her ragged clothing, her urine soaked couch, the post cards she asked everyone to send her when we went on vacation, her holiday decorations, her brown bananas, her broken laundry basket, all of it out to the dumpster. There was no one there to fight over her things. She had so little and no one who wanted it. She would die alone. The county would pay to bury her. Social workers would plan her funeral, write her obituary, notify Social Security, the Veteran's Administration, CDA, and Dane County Social Services that she had died. The bank would retain her $80 and when no one came to claim it, it would be put in the funds for the public schools. It just seemed like there should have been more - more of a fuss, more of a ripple, something that was changed because Alice had died.

I wish there was some way I could sum up her life that would make me feel good about it. "She lived her life and died on her own terms." That's what I wrote for her obituary. But it's not true. She lived her life on someone else's terms, someone born normal. That's the truth.

The last time I saw Alice she asked me, "What if something happens to me while you're gone?"

"Oh Alice," I replied, "you have lots of people you can call." But Alice knew there was no one, not really. She was alone. She needed to fight for everything she got throughout her life. Nothing was given to her unconditionally. She was dependent on the benevolence of others. Her relationships were fractured, fragile and had conditions placed on them - Don't call me at home. Don't stay too long. Don't act crazy. Don't get mad. Do it my way. Alice's life was hard and her death made barely a ripple. It wasn't enough.

July 1990 –Kathy Lemke

Memories of Alice

I've always felt the phrase "larger than life" a good description of Alice. It seemed that her presence totally surrounded you. Rarely were you in doubt as to whether she felt happy or sad, angry or cheerful.

If she crossed your path more than once, you knew her. My aunt lived within three blocks of her for a while and they were both bus riders. While my aunt had never met Alice she *knew* her. I mentioned I hadn't seen Alice around for a week or so and my aunt told me Alice had had to move—she now lived on McCormick Street. I said, "Oh, I didn't know you talked with Alice." She said she hadn't—the bus driver had known Alice well and he had passed on the news of how she was doing in her new home.

As the person who answers the phone at Options I had quite a bit of experience with Alice in all her moods. Most always Alice knew precisely who was scheduled to do what with her and exactly when—but always felt it necessary to check to be sure that it would happen precisely the way it was scheduled. While she may rarely ever have said thank you to any of you for the help you gave her, you *knew* you were important to her. You were indeed her lifeline. You *knew* because when staff members changed, went on vacation or moved away her anxiety was frequently and loudly expressed. Her visits to your homes were bragged about often. Her constant telephone calls to you for reassurance were as eloquent an acknowledgement of your importance to her as any thank you would have been.

Alice and I shared the problem of diabetes. She had many questions and thoughts to share with me at first—about where to stick herself, about feeling funny, about when to eat—NEVER about when NOT to eat. She understood very well that she was not to eat foods with sugar, that she was to eat after taking her shot, that her meals were to include meat and vegetables and no dessert. I could generally tell without questioning her how well she was following these routines by how our conversations would start. On the good days—I had chicken for supper last night, vegetables, good for

me—is Kathy there? On the bad days—You don't know everything you_! You don't need to tell me anything! You just put me through to Ellen! It's called the right to choose and Alice understood she had that right. The mother in me understood that I couldn't make her choose right, but I sure did raise the guilt level!

Options had very few calls from Alice during the last weeks. You had begun seeing her every day and while that in itself didn't always assure that she made the so called "right choices" it did give her security—she no longer had to anxiously call Options many times each day. She called only three times the last week and then just to make sure everyone was aware that Gail the Director was coming to see her while Kathy was on vacation.

My last view of Alice was out at East Towne about 8:30 at night. She was leaning on the counter at the Cookie Factory. The two young girls behind the counter had their heads close to hers and they were deep in a discussion of the various cookies on display. My first impulse was to dash over and try to drag Alice away from the evil sugar. But as I watched their quiet, totally absorbed conversation, I thought to myself, "Sit on it Mom. She's not even buying. Let her enjoy." There's a little bit of guilt for leaving her in such a place without fighting to draw her away from temptation, but only a little. Most of all there is a deep joy for Alice for having that moment in time—a quiet conversation with two young people who weren't laughing at her, but were truly listening and responding, completely tuned in to Alice herself. What greater joy could we wish for our Alice than that?

June 1990 —Carol Lofgren

I Will Miss...

When I got the call that Alice had died, there was a part of me that felt disbelief. Even though Alice had been living how she wanted to and basically abusing her body for several years, she was such a fiercely independent and spirited person, that I really thought she may outlive me. The reality of her death has left me very sad. In thinking about what I could say about Alice, I realized that it is not possible to catch anyone's many facets in a few minutes. I found myself trying to say in five minutes the accumulation of our five-year relationship. I decided that I would focus on the things about her that I will miss the most.

I spoke with Alice on the phone nearly every day in the last five years, sometimes several times a day. I will miss her information. I learned what was going on with people we knew mutually, as well as people I have never met—as I'm sure many of you knew the intimate details of my life. Alice loved talking with people and finding out what was really happening in their lives, and she never hesitated to pass on whatever information she had—who was sick, well, on vacation, changing jobs, tired, poor, etc. Since I moved from Madison, Alice had been my lifeline to what was new with my friends and her friends here. Without talking to anyone else, I felt connected to dozens of people through Alice. I will miss the news.

I will miss Alice's sense of humor—particularly her ability to see the ridiculous and laugh at herself. I remember one time when Alice had missed an appointment with someone to talk about a job. She was walking down the street when the woman drove off. When I talked to her later and told her that the person hadn't seen her walking, she exclaimed loudly, "What do you mean she didn't see me? Look at me, I'm as big as a house!"

I will miss her spirit and fortitude. With Alice, you were never in doubt about what she thought about a situation. She called it like she saw it and stood firmly behind her opinions. She challenged me to examine what was important and to not accept rules simply because they were rules. She was the best person at getting what she wanted that I have ever known. Her ability to seek out and establish relationships is in itself a tribute to her inner strength considering the countless broken

relationships she had in her many years of being moved from place to place. I will always remember the lessons of how resilient the human spirit can be that she taught me.

I will miss watching her play with my daughter, Katy. She was very tender and nurturing with Katy, or Tootles as she called her. She was responsive to her needs and looked forward to seeing her and talking with her on the phone. It was a side of Alice that not many people saw. As scattered as her own family was, Alice was very clear about what a family should be. The concept of family and belonging was very important to her. Even though she only lived with family members for a few years while growing up, many of her fondest memories were of those times. Alice became a part of our family—concerned about not only Katy, Jack and I, but our cats as well. I am sad that Katy will not be able to grow up with Alice as a physical presence in her life. I know her life would have been richer for it.

Finally, I will miss her anger. As frustrating as it was at times, Alice's anger was a part of her, and was a product of the lack of control she had over her life and many years. I always felt that Alice's anger was also one of the ways she expressed her caring. I took comfort in the fact that if she really cared about you, she felt safe enough to get really angry at you.

Alice, I hope in your new life there are cigarettes, peaceful places to sit and rest, a community to belong to and unlimited cups of free coffee. You will be missed.

June 1990 –Sarah Salzwadel

I've Never Heard So Many Nice Things Said About Alice

Since Alice's death I have had many feelings about Alice, our work and people's situations. The first feeling, as obvious in the title, is cynicism. It is more than ironic that faced with so many struggles and isolation in life that Alice's death seemed to go so smoothly. People were willing to meet our every request in planning Alice's funeral and burial. Even the Pastor was willing to skip the "what you do to the least of your brethren, you do to me" eulogy and actually proclaim Alice a saint. Hardly a label bestowed on her during life.

Her three aunts and an uncle who had little to do with Alice during her life drove six hours to see her get buried. Equipped with a Polaroid in hand they took pictures of Alice in her coffin, they wondered why they didn't know Alice was ill, and offered Kathy four dollars for all her hard work.

It's almost too easy to feel cynical with all the outpouring of nice things said and people's accommodating ways. In reality it was all Alice and those around her could do to keep her in an apartment for a year without the threat of eviction.

Another feeling I've had is sadness. I am sad that Alice is gone. The last month I saw Alice every Friday. It was an hour every Friday spent smoking cigarettes, filling the bird feeder and listening to Alice talk about everything from Sarah to wanting to die. The sadness of missing Alice will pass, the stories of Alice will be told for a while and then they too will pass. It also saddens me the poverty that Alice lived in. The poverty of material possessions, the poverty of isolation, the poverty of being so vulnerable. While Alice lived and died on her own terms both were a constant struggle. A struggle she faced because of who she was, where she had lived. A struggle of abandonment. A struggle of lack of worth to others. A struggle of being retarded. She struggled through life by fighting, the fighting brought on more struggles. It saddens me that this was the life and death of Alice. It saddens me that it is the life and will be the death of other people we know.

Finally, I feel a sense of relief. Many people said how better it is for Alice now... there is the relief for Alice. I also feel relief for myself and my team. When she was in the best of health it was not an easy task helping to support Alice. Over the last year as her health became worse and worse the task of taking care of Alice took a lot. It is hard to take care of someone who is dying, be it a family

BEST COPY AVAILABLE 139

member or member of your community. After Alice died I felt a sense of relief that we no longer had to struggle with Alice through a very difficult time. As we as a community continue to take care of each other through sickness and death and experience the difficulty that it brings, there will be inside a sense of relief. It is a feeling I don't think we should think of as bad or one to cause guilt. It is real and it is OK.

July 1990

–Sid Nichols

Teachers

Some support workers meet a teacher among the people they assist. These teachers don't give lectures. Their actions disclose important lessons to people willing to become their students. Like zen teachers, they can be disturbing people to learn from.

The Bottom Line

Friday's bad news came from Peter - Christine had lost her job. This was the "perfect" job at the video store, the one we all had waited and lobbied for with Goodwill for months. She was let go because she refused to accept minor changes in her work routines.

My response was overwhelming disappointment and questions as to why it happened. Did she really have so much trouble adjusting to even small changes? Was work unimportant? Wasn't extra money earned important to her? Was it that she preferred spending time hanging out with Options' staff? If so, were we then contributing to the problem by being so available to her?

Chris did not seem particularly concerned or upset about losing the job. Not for the first time, I was acutely aware that what other people badly wanted for Chris she didn't necessarily want for herself. I prepared myself for the weekend phone calls I was sure to get from her. I would be honest about my feelings of disappointment, try not to be judgmental, but at the same time be firm about our expectation that she ultimately work. Surprisingly there were no phone calls Friday night, then none on Saturday. By Sunday I was really beginning to wonder. Is she afraid to tell me or what? Finally the call came: 7:45 a.m. Monday morning.

I gave her my advance prepared comments. Surprisingly she listened without defensiveness or anger. She was rather speechless. I was really aware that I was mad at Chris for not meeting *my* expectations for her. I thought a lot about what's realistic for Chris, given her history, the balance between having high expectations and accepting people for who they are and where they happen to be now.

At 8:00 p.m. last night Chris called again. In a tentative voice she said, "I just have one question I want to ask. It's hard to ask this: I know you're disappointed about the job, but I need to know if that means you think any less of me as a person... I really need to know."

"Of course not," I answered. "I still like you a lot and that's not going to change."

"Oh, good," she relied. "Now I'll sleep a whole lot better tonight."

Once again, Christine brought me to the bottom line.

October 1988 —Gail Jacob

"Ruttle, Tuttle, Fresh and Fruitle"

The calls from Christine during her first few days of this most recent stay in jail were typically frantic. She worried about how long she would have to be there, about the possibility that the judge would stipulate a change in living situations, about relationships with her neighbors and apartment manager. After the decisions were made: 30 days in jail and permission to return home afterward, Chris settled down and the quality of our phone conversations changed considerably. She was very reflective and insightful about what led to the jail term. She was counting the days until she could leave and let me know each time we talked how many days were left: 21 days till I get out, 14 days, 9 days, 4 days.

In fact her waiting took on a peaceful, almost Zen quality. It surprised me at first, since I imagined myself on the verge of a nervous breakdown had I been in her shoes. Then I remembered visiting Carol at [the psychiatric hospital] and registering similar surprise at her calm in the midst of that

chaotic dayroom. It was humbling to realize how expert these women were at "doing time" and to note that they spent many more years locked up than being free. They knew how to survive the endless quality of empty time and, for the most part, how to disconnect from the insanity around them, protected by the visions of "when I get out..."

Chris called on Thursday, the day before her release to say, "I'm not counting the days anymore, now I'm counting the hours."

"So what are you going to do when you get out tomorrow?" I asked.

"Well, I get out of here at six in the morning and I'm going right down to the International House of Pancakes and order the ruttie, tuttie, fresh and fruitie special breakfast. I have just enough money to pay for breakfast and take the bus home. Then I'm going to go to my apartment, take a shower, put on a record and just lay on my very own bed."

Ruttie, tuttie, fresh and fruitie... I was intrigued. When Chris called on Monday, I said, "So did you get to the I HOP on Friday?"

"You bet I did," came the reply.

"So, did you have that special breakfast?"

"Yes, I had the ruttie, tuttie, fresh and fruitie, just like I planned."

"So what *is* it exactly?" I asked.

"Two eggs, two bacons, two sausages, two pancakes with blueberry, strawberry or cinnamon apple toppings," she replied, not hesitating a second.

"I bet you had coffee, too."

"Yup, I had enough caffeine to choke a horse!"

"And you ate the whole thing?"

"I gulped it up in five minutes... I was bound and determined not to get a doggy bag either. I ate the whole thing, not the plate, just the stuff on it. That plate was spotless clean when I got done."

"That's a lot of food," I said in wonderment.

"Yea and it only cost $4.62, including the tax. I'm not supposed to have cholesterol, but at the time I thought, "Who cares about the damn cholesterol?"

I could tell Chris was in heaven just with the memory of it.

"You know, Gail," she went on, "when you want to treat yourself to something special, your best bet is to find something that's open 24 hours a day. When I want to treat myself to a breakfast I know just where to go and how to do it."

March 1989 —Gail Jacob

A Lady with Guts and Sensitivity

Alice is one of the most amazing women I've ever met. She's had more life experience in her fifty-some years than most of us put together. She is a survivor and an extremely resourceful woman who has a positive outlook on life, a keen sense of people, a love of family, and a good sense of humor.

Her non-stop conversation merges the past with the present. She speaks lovingly and longingly of her days with her Aunts Gert and Grace. She speaks matter-of-factly about the foster family that mistreated her and she "kinda misses" [the facility she used to live in]. What she misses is the sense of community, of belonging that is very important to her.

She is connected with people all over the city and it's all been her doing. She knows the security guards at the shopping mall near her home. She knows their names, their work schedules, their family situations and she cares about them.

"Kevin's not working until Monday," she reports. "He needs time off too, you know. He has to study for exams."

The librarian has the WSJ and the Cap Times ready for her when she comes in. Alice tells me the librarian sent her home early last week.

"It's going to get pretty cold tonight, Alice. Better get home where it's warm."

When I take Alice grocery shopping at Sav-U she enlists the manager to help her pick out the meat that best suits her taste and fits into her budget. At the check out line the clerk asks, "How much money do we have to spend today, Alice?"

"Twenty five dollars," she answers.

"OK, give me the things you want the most first."

Together they begin the process of pick and choose, what food gets bought and what gets put back. At one point the clerk holds up a liter of pop. "Do you really need this?" he asks. Alice's eyes meet the clerk's. They both smile. "Why sure I do," replies Alice.

We seldom go anywhere that Alice does not see someone she knows. And I've watched her start conversations with strangers. "Hello, how are you today?" If they respond, a conversation follows. If not, Alice will lean toward me and comment, "That person's kinda crabby today."

Alice knows this city much better than I do. While driving what I consider to be a direct route to somewhere, she'll yell, "Where ya going? You shoulda turned there! Oh, boy, here we go - takin' a ride." And she's right. I should have turned there. Alice knows how much coffee and dessert cost in every restaurant in this city. She knows who gives the second cup of coffee free and who doesn't. She knows where free meals are served, when, and is on a first name basis with those serving them.

One day she said to me, "I've been in jail a few times."

"Why were you in jail?" I asked.

"For being crazy."

"You're not crazy," I said.

"Some people think I am."

"Do you think you are?" I asked.

"In some ways, I'm crazy," she answered.

Crazy or not, Alice is an amazing lady, a lady with guts and sensitivity. And I feel fortunate for having met her.

–Kathy Lemke

With Intense Eyes

With intense eyes Jane stares at me across her dining room table.

"I never got to go out with my brothers and sisters when I was a kid. They were always trying to protect me from the dangers outside my home. But the danger wasn't outside my home; it was within it," she says with emphasis.

This past year I have often sat across the table from Jane listening to her process her relationship with her family making one profound statement after another. It has been an incredible amount of work for her seeking out truth and deflecting blame, coming to terms with the past and finding value in herself and the future.

"When my nieces were born, I wished they were boys so they wouldn't have to go through what I did. I told my brothers I wouldn't be responsible for what I'd do if anything happens to my nieces." Jane's eyes begin to water and she stops.

"Are you angry with your brothers for not protecting you when you were little?" I ask.

"I'm angry with God. If God knows everything and he made everything, how did he let my dad do this to me?"

After a pause Jane adds, "Is it OK to be angry with God?"

"Who could I have told?" she asks. "Who would have believed me? I almost told my special ed teacher. I mean, I did things to get people's attention, but I couldn't tell them. My dad said he'd kill me if I told anyone. What if I told my principal? He might not have believed me because I'm handicapped. He would have asked my parents and they would have said I make things up. My dad would have killed me."

Jane's father died several years ago and a wedding picture of her mom and dad sits on an end table in her living room. I don't know why it's there but I do know Jane desperately wants to feel a valued member of her family and she wants her mother and her brothers and sisters to acknowledge the truth and say she's not to blame. Her family wishes Jane would stop discussing private matters with strangers and would just let it die. They say she exaggerates and has always given double messages. The family, it seems, sees Jane as a reminder of something very uncomfortable and they, too, want to deflect blame.

I stare at the wedding picture while Jane talks, not really to me but to herself. "I didn't know. I thought I had to have sex with my dad to get my monthly. I didn't know. Whenever I'm with a guy I feel like my dad is there telling him what to do. That's why it's so hard for me to say no to a guy. I am afraid he'll hurt me."

Recently Jane was feeling very proud of herself because she had stopped seeing a man she felt was only interested in having sex with her. She's beginning to wrestle with questions like, "Why am I only attracted to men who want to use me?"

In this past year I have watched Jane wade through her pain to come to some immense growth and I am again awed by the human capacity for healing and survival. Jane has also helped me think some about blame, that destructive hot potato we pass all over the place when what we really need to do is get rid of it. Blame is not something that comes from within us. It is placed on us. And to accept it is to challenge our self-worth. Fear of being blamed stops people from acknowledging truth.

I heard an interesting comment recently concerning Ron and his difficulties with employment. It went something like this: "We blame [the day program]; [the day program] blames Ron; Ron blames the voices."

November 1989 —Kathy Lemke

The Power of One

Over the past six years there have been more than a few times when I have questioned why I stayed on at Options and I have always come up with an answer. The incredible feeling of purpose that exists at Options is a powerful force that brings me back into focus when everything gets blurry.

That is why I found it so hard recently to figure out why I was having such a difficult time at my job. I was lacking energy and creativity. I felt listless, bored, distracted, restless over all. My communications with co-workers seemed forced, I was having a very hard time expressing myself and so I kept things inside to the point of frustration. I felt that I was frequently rude to the people I support and began to wonder if I was really providing that support. The best way that I can describe the feeling is that I was blocked. There have been times when I have been able to literally feel the rhythm of this work flowing through me. I just couldn't feel it anymore.

For a long time now I have been able to come up with excuses for where the feeling came from. First I blamed it on the fact that I had made the decision to get married and therefore didn't know if I would be able to remain in Madison after that point. It was difficult to think long term, not knowing if I would be here much longer. After I found out I could stay, I blamed my state of mind on the distraction of planning a wedding. How could I expect myself to concentrate on my job when there was just so much other stuff going on? Well, the wedding came and went but the feeling just didn't go away. I sort of started to feel like a ghost who hangs around but isn't quite a part of things. Why couldn't I get it together?

Things finally seemed to fall apart for me this past weekend. At a ceremony I attended on Friday I asked for spiritual guidance to find my way through this and that my eyes, ears and heart would be open to the signs pointing me in the direction I should go. When I woke up Saturday morning I decided that the direction was to quit my job. The answer was that I was burned out. Before I destroyed everything I worked for I had better just leave. I talked with my husband, my best friend and my mom. While no one seemed as sure as I was about my decision, everyone pledged their support that I should do what I needed to do.

I left my house Monday and drove to work. I cursed the fact that on Sid's birthday I would be presenting him with this wonderful piece of news.

But when I came in the door there was Chris. Her voice said, "I'm trying to stay away from the construction workers because I don't have to work this morning." Her face said, "I know I don't have an appointment but I'm really anxious and I hope you have some time to talk to me." And my heart said, "I'm sure glad to see you Chris, come on up." That was when my power switch clicked back on.

Chris, I know I told you when you left yesterday morning that you didn't know how happy I was to see you when I walked in the door, but now everyone here does. Thank you Grandmother Moon.

November 1990 –Amy Lutzke

Learning Experiences at Options

I have come to learn over the years that I am a "helping professional". I'm a professional, or at least training to be one, with a goal to connect labeled people in the community. I, with my labels (student, social worker, professional), am to help other people, with other labels, to connect.

Here are some excerpts of what has happened:

Judy is someone who many people consider a "loner". To the extent, in fact, that family and work associates have expressed concern. Last December Judy and I went shopping downtown. During our short trip I witnessed Judy being greeted by, and greet, about seven people... A short time before that I met Judy downtown for coffee. I found her laughing and telling stories with friends and chatting with the restaurant staff... More recently, we stop at a donut shop to get coffee where she introduces me to her friend behind the counter...Another time, I'm at her apartment helping her move furniture, wondering what to do as I come across one rather heavy piece. Without a thought, Judy heads down the hall to recruit a neighbor, and the job is done...

I think of Debby over the cold weekend and assume she's home alone with the TV blaring or drawing. I look forward to asking if she'd like to join me to see a free play I'd just been informed about. Debby tells me she was over at a friend's house this weekend. And about the play, well, she's just got too many things coming up, what with the church banquet, the circus, and a dinner with her club...

I often try to think of people and places to hook Kathy up with. I went Christmas shopping with Kathy also, who saw and chatted with two friends within the first ten minutes of our being at the

mall... I watch Kathy around her apartment building, engaging with so many people, and often riding over to the next building to chat with friends...I go to the doctor with her to "facilitate communication" - while there each staff person greets Kathy and inquires about her life, and while her leg is being examined Kathy engages in a lively conversation with the doctor...

I often inquire about people's family involvement...Judy tells me about her visits with her family every few weekends...

I make it to my mother's house in Minneapolis three, maybe four times a year...

I know two of my neighbors, and that's only to say hello...

When I go downtown, or to the mall, it's a rare surprise when I see a friend...

And the people who wait on me, serve me, check me out..are nameless faces...

When I began my placement here, I looked at it as an opportunity to learn skills, and learn "the system", but I could not imagine back in September the range of learning I could, and would experience.

I hope I will have some stories of my own comparable to these I've heard around this table in terms courage, strength and perseverance, of people overcoming "insurmountable" obstacles, and I will continue to be inspired by these three women.

I think Kathy sums it up when I call her to get together, to check on things, and to "help" her with certain life activities. I cheerfully greet, "Hi Kathy!" (with an unspoken, "This is your helping professional."), and she responds, "Hi, what can I do ya for?"

...help me to be connected, Kathy...

February 1988 –Maureen Quinlan

On Words of Power

In the fall of 1988, several Options staff members attended a conference about community building which included a discussion of "words of power." Words of power symbolize vital sources of meaning for a person. These symbols energize a person and organize the person's actions. At their suggestion, Options staff identified and wrote about their own words of power.

Liberation

Liberation is a theme that has been present in my life since my earliest memories. As a small child, I heard my parents, both survivors of the holocaust, tell stories of liberation from the death camps in Germany and Poland. The images created by their memories have shaped who I am as a person and have influenced my work in ways I've only begun to understand in recent years.

Four years ago Options became part of a new effort to bring people directly from state institutions to their home communities. This experience helped me to understand how our work was part of another liberation movement. I even remember the moment that this connection was made for me. It was a welcome home party for Darwin, a fifty five year old man, on the day of his arrival in his new home after 47 years in a state institution. As I entered his apartment I saw the flowers and gifts, the kitchen table filled with food. There was laughter and a sense of excitement among the small group of people who gathered to celebrate this truly amazing occasion. I then saw Darwin for the first time: I'll never forget that picture of Darwin in his wheelchair, laughing, arms waving, blue eyes flashing. On his tray in front of him was a huge bowl of home made broccoli soup, a brownie and a can of Budweiser. Though we were all strangers to him and though he couldn't tell us in words what he was feeling, we all knew that Darwin knew he had come home.

I understood then about the similarities between my parents' story and the stories of people who are labelled who have been locked away, deprived of their dignity and their very humanity. I realized in a very deep and personal way how closely my history and Darwin's were bound together.

As time goes on, I am learning that liberation is something that goes far beyond the actual freeing of someone from an institution. That is perhaps the most dramatic act. But it is also just the beginning of a long and mysterious process. There is also an internal letting go that happens over time, sometimes after many years, in which there is an experience of personal healing and transformation which can seem miraculous.

I don't understand the process, but I have seen incredible changes in people over the past fourteen years. I am reminded of Ken, a man 43 years old who lived 25 years in an institution and who, for most of the past four years spoke few words and showed little emotion. Then suddenly, in the past two months, he has begun to talk. He talks with animation and excitement. He asks questions. He talks about his day, about what he likes and doesn't like. He tells you what he wants. What unlocked the door? Why did it happen now? What changed in his life?

The process is magical to me: a setting free of the human spirit, if you will. I think it has to do with trust and feeling safe. It's about having space to try and fail, to have choices and control and it's about being treated with dignity and having continuity and security and being cared for. The liberation story is a humble one. It's about the everydayness of being with people over time. For the workers at Options, we offer that continuity and security through often routine tasks that guide people through the complexities of community life.

I think what we can do for people is to help create that space for the flowering to happen. We can nurture that seed, feed it, give it space and hopefully in its own season it will blossom.

Approaching our work as part of a liberation movement helps us to move from a place of "power over" the people we support to one of "power with". It restores a sense of dignity and a spirit of passion to staff whose work is often as devalued by society as the labelled people with whom we

work. It has also helped us to question the ways in which we work together and how we organize ourselves.

I'm learning that this process of liberation is *not* something we as professionals are doing *for* people with disabilities. Most of us carry some form of oppression within us as a result of our personal histories and the political and cultural context in which we live. The lessons I learn professionally are really lessons in life. My own liberation story is very much interwoven with the stories of the people for whom we work. We are on the journey together.

December 1988 —Gail Jacob

Reality

Reality is an agreement between people about what life is all about. It depends on trust between the people who make the agreement, and its purpose is to limit as much as possible the chaos that life can be.

I am continually facing chaos, in my personal life and in the office. The agreements I have made with the people around me about reality are often very tenuous. There is uncertainty all around — What will happen if the MA dollars are challenged? Is it really a good idea for Dillan to go live with his Dad? Are we really helping all the people we can at Options? Did I feed the cats this morning, because if I didn't they're going to throw up? Is this phone call really an emergency?

When I compare the way I live now to the way I thought I'd be living when I looked ahead with the hope, determination, naivete and certainty of a teenager, I am amazed, because I am living no differently than I did then. Then I was at the mercy of parents, teachers, and the whole rest of the world. I thought I would take control when I grew up, and simply wouldn't allow things to be wrong, and this dream led me through those chaotic years. But now, life is still the same: I live from day to day, week to week, squeaking through, never quite finishing, never sure where I am going, and all the time following dreams that really haven't changed all that much. I am not sure that those dreams will ever become reality, and I am not sure that this is a good way to live, but it seems to be the only way possible.

Then, when I think of Options' mission of enabling people to live regular lives in regular places and of the incredibly high standards set by Options in deciding whether these goals have been reached, and when I compare this to my own life, I wonder how realistic the agreement is that Options' reality is based on. Is the reality of Options something that can really be achieved? Is it only a dream that keeps us all going? Is it the only possible dream we have to follow? Is this the reality we want? I don't know the answers to these questions. I don't know if anyone ever will. But I think we need to keep asking the question of what our reality is. Maybe someday we'll know the answer.

September 1989 —Polly Molenaar

Open

"Open" is a healing word and a word so important in community. Pain can often be lessened by visualizing openness in a particular area of the body. Openness can heal emotional pain as well.

About seven weeks ago the power of the word "open" emerged quite dramatically when Betsy was in labor and we were about to have our first child. During strong contractions it was soothing for Betsy to visualize her body opening in a very normal way. She asked the midwife and me to remind her, when the pain came, to concentrate on picturing herself opening. Even forming the letter O while breathing and vocalizing seemed to do wonders for the birth canal.

When Hannah was born, openness was everywhere. All six of us there welcomed her. The first thing I saw her do was open her eyes. Her lungs opened. Her mouth opened. Her limbs, held tightly in the fetal position for months, began to stretch out. Then she was placed on Betsy, whose arms were open wide.

Since then, the meaning of "open" has come to mind often. I've been thinking of community, and how my vision of community has to do with a lot of things being open.

The opposite of open is closed, and in my vision of community people don't have closed ears, closed minds or closed doors. Closure excludes. Closure prejudges.

Open (continued)

It's been about nine months since I first wrote about the word "open." A few weeks ago I realized I had forgotten how powerful a word it is for me. My community was opening up to me, but I realized that my heart and mind were closed a lot by stresses in my job. A wall existed that circumstances and I had created.

It seemed impossible that everything which needed to happen would happen. Mary was leaving and Chris would need a new Home Support Worker. Mike needed to find a foster home, but only people from Stoughton and Sun Prairie were calling. Bev had to fire her Live-in without notice. The list went on. Paperwork was piling up. Response to ads was low. I felt like my head was just below the surface of the water.

It wasn't until the end of August that I found the clarity to remember about opening. It was the kind of opening that happens when you stand on a beach with your toes in the sand and the wind blowing hard and you take a deep breath and look out to sea and believe that things happen for a reason. Some things that happen are good, and some aren't. And if I can open myself up to the possibility that these things will work out for the best, then that possibility becomes a probability, and then it becomes real. But if I keep this wall up, this wall of doubt, of too many things to do, then I can't hear the waves, I can't smell the salty air, and I can't see the sun's reflection in the water.

Well, all around the same time a bunch of wonderful people showed up. Chris met Becky. Andy and Don met Jeff. Bev met Cassandra. Mike met Pranee and Joe. Jean met Pat. And there are others out there we haven't met yet, but we will.

I'm not finding it easy to describe this phenomenon, largely because it can't be explained. I just know that reaching a point where things flow comes about from opening myself to allow it to happen.

December 1988 & September 1989 —Peter Bazur-Leidy

Surround

Surround is a power word in my life both in an active, supportive and a passive, restrictive sense. To surround —to enclose, to envelop, to invest, to encircle can be a marvelous gift of support and love or a barrier of enclosure that is sometimes difficult to overcome.

I come home each evening to a house that gives me great pleasure - in the way it looks, the living space it provides, the twenty three years of very pleasant memories it holds. The pride of ownership, of successful decisions regarding its repair and maintenance have done a lot to improve my feelings of personal worth and competence. It is, however, also the site of the greatest tragedy of my life - my husband's suicide. As such, it also encloses and envelops me with feelings of sorrow, failure, and rejection. The joys and sorrows of these very familiar surroundings lead to a roller coaster of emotions that are very hard to keep in perspective.

I go to work each morning with a group of people whose job it is to surround the people they work for with emotional support, the feeling of self-confidence, knowledge about choices to make, celebration of successful choices and help sorting out their lives following the not-so-good choices — all this done while giving these people at least the illusion of independence. They also surround each other with support, with advice, with laughter, with the value of what they are doing for others and with themselves as caring people. To be invested in Options as a place to work is a very positive side of surround.

My community consists mostly of family - my mother, three children, a son-in-law, two grandchildren and an aunt. Seven of these eight people live within ten blocks of my home. This closeness has the advantage of surrounding me with unlimited love and support if I ask for it. It has the disadvantage of surrounding me with seven differing opinions of what I should and shouldn't do. Mainly it requires of me the very essential discipline of politely listening to and considering seven views of whatever is being discussed and forces on me the courage to make a choice. It also creates a barrier between myself and the larger community which is difficult to overcome. If I need company there is no need to reach beyond family. If there is a choice I don't want to face, I can always open it to family discussion which prolongs decision making, sometimes indefinitely. If there is an outside activity I'd rather not attend, I can always find an excuse —I have to babysit, spend time with my mother, do something for or with my children.

Surround —a marvelous gift of support or a barrier of enclosure— a powerful choice to be made each day.

September 1989 –Carol Lofgren

kon - 'trib - yut

> **contribute** (kon-'trib-yut) [L contributus, pp. of contribuere, fr. com-+ tribuere to grant, bestow, fr. tribus tribe] vb. 1: to give or supply in common with others la: to give a part to a common fund... b: to play a significant part in bringing about an end or result.

I consider the reciprocal nature of the word, contribute, to be the life's blood of my sense of community. The origin of the word itself implies a coming together for a common purpose. In my own definition of this word it is the sense of balance, giving and receiving that creates its power. I give of my labor, my time, my finances, my goodwill, my love, to my community of home, town, family, friends, and neighbors. And they all in turn give to me... support, beauty, opportunities, challenges and so on. The contribution of individuals becomes the cumulative contribution of the whole. There is power in that —as I believe that "wholeness" of contribution has not only an additive effect, 1+1=2, but one of potentiation. 1+1+1+1+1= an immeasurably powerful end, the result being a greater product in unison.

The challenge before all of us is to recognize individual contributions... and to incorporate it into the community whole. Some folk's contributions are more easily seen than others... but we need to recognize the contributions of all. We can't always see it with our eyes or hear it with our ears, we need to feel it with our hearts. Then we need to be open - and receive it. For it is only in the gift of receiving that a contribution can truly be made.

September 1989 –Leslie Wilmot

Revolution

From the Latin *revolutus* - to revolve

When I first heard people here talk about words of power, revolution flashed on the screen in my brain. I thought about why this word would hold power for me. Revolution. It sounds strong. It made me think about acts of rebellion, overthrow, dramatic change, a seizing of power.

It wasn't too difficult to tie this to my work here at Options and even before I came to Options. Much of what I learned, of what interested me in school, was not the technical aspects of teaching. I frankly found the lesson plans, the indirect physical prompts versus direct verbal cues, the futility of teaching kids who lived in [the institution] to be somewhat frustrating and tedious.

What I found myself thinking about was the revolution in which I was enmeshed. A parental revolution had brought about the legislation that got these kids into school in the first place. The people at the University were revolutionizing how to think about teaching, about special ed and about people with severe disabilities. They espoused regular paying jobs instead of sheltered workshops. They preached keeping kids with families instead of sending them to institutions. They wanted these children to be able to eat at McDonald's like the rest of their peers and they daringly insisted that teaching people how to order a Big Mac *was* relevant curriculum.

As my experiences in this revolution increased I felt myself moving away from my focus as a teacher and thinking more about the possibilities in lives of people with disabilities. I began to see that skills alone were not what we wanted to achieve here. Everyday I saw kids learning, achieving, growing. But I saw them do it in segregated classrooms. I saw them surrounded by teachers, aides, and job coaches, not other students or co-workers. No matter what skills they were taught they were *still* separate.

Some how I ended up here at Options. When I came here I was still pretty enmeshed in my teacher/trainer frame of mind. I knew something wasn't quite working right in what I was trying to do but it wasn't at all clear to me what it was. Over the past five years I think I have gotten closer to helping people realize some of the possibilities that I first began thinking of years ago.

There has been a lot of personal growth involved in making that happen. I have received a lot of help from co-workers, the people we support and the pool of revolutionaries with which we associate. I have learned to give up much of my need to control situations and people. I've learned that people usually know what is best for themselves. I have learned to listen. I have learned a lot more things but that's not what this story is about. It is about revolution.

Revolution: activity or movement designed to effect fundamental change in the social structure.

Are we directing a revolution? No, I don't think so. Are Darwin, Chris, Rita, and Terry directing a revolution? I would say they are. Their very lives day to day are living a revolution. It is a slow change, one that will continue for an indefinite amount of time. Some of us are trying to imagine what this revolution might look like when it's over, but I don't think we really know. That, too, is because it's not our revolution, but theirs. People with disabilities are effecting change in their own lives. They are taking risks, making choices, accumulating power. Me? I see my job as helping them to continue to do that. My job is to support the revolution.

Finally, when I sat down to write this story and said the word revolution to myself another meaning occurred to me. I thought of revolution as a form of the word revolve, to turn around a center.

As I continue on the orbit around the center of my work, my thoughts about what that work is continue to change. But it seems that I stay on the path and that I am held in this position by a kind of gravity. I would like to come back to this story five years from now to compare where I am now in my revolution to where I will be then.

September 1989

–Amy Lutzke

Choice

It can be a strange thing when we have things we need to do (or should do) and the reactions we have or *choices* we make to accomplish those things. Take, for example, the "assignment" we all had to do last time regarding our "power" word and how it applies to what we do here at Options. Most people had the reaction of - "Oh, God, not that," or "What will I write about?" For some it was an easy choice. For others it took some thought, and yet for me, it was sort of a mixed reaction. I knew my word would be "choice" since it is something that I think about a lot when I'm working, but it is also a process that can be complicated by many factors - some controllable, and some not. Often the choices I make are influenced by outside things I can't control, and other times the choices I make are very deliberate and thought out. Perhaps my not being prepared was a choice I made so that I would have time to think of something great to write about, but it's a funny thing about choices - whatever ones you make influence the opportunities that follow. Be that influence good or bad, each situation that follows comes as a result of decisions we made before, or decisions we didn't make, or things we didn't do. In my case, that's not all bad, since now I am in a place to see that my making a *choice* not to be ready last week has opened up a new opportunity to think about something I hadn't considered in a long time, and relate that to my work here.

It's also a funny thing about choices - they are really influenced a lot by the times, people, past experiences, and insight for the future we all possess. Take for example Sue - it's certainly not her choice that she's had four or five different attendants over the last couple of months to get used to, to see them quit, and sadly start the interview process all over again. Yet for now, she's made the choice to roll with it, re-arrange her schedule so we can interview new people and train them, and be generally good-humored through it. That process is a part of Sue's past, and that influences her now. She's said we'll find someone, and as she said this morning, "Even social workers can come in and do this stuff" as Metro Plus was waiting outside (as patiently as Metro Plus can) while we finished up showing a new attendant what mornings around Sue's house are like.

That's a choice, whether Sue thinks about it consciously or not, and that attitude will certainly influence our chances of finding the right person to work with Sue, and increasing the likelihood of their staying with Sue long term. As I said before, choices made affect the future. As I also said before this story would relate my work to something I hadn't thought about in quite some time. That story is one of my family - in particular, my grandfather, and a choice his family made nearly fifty years ago.

My grandfather was the oldest child among six children. His mother died when he was very young, and he really took on a parental role to help his father care for his five younger siblings. We all knew that he had done that, yet my father, aunts, cousins and I had only heard about four of my grandfather's siblings. It was not until last year when I had a class and had to do a family history, that I found out about my grandfather's sister. This sister has led a completely different life than any of the other siblings as a result of a choice her father, and then my grandfather made. It seems that "Maggie" had some sort of mental illness or something that made her difficult to live with. As a result of the times and attitudes of the early 1920's Maggie was put into an institution. That was 1926. Obviously that choice was influenced by the lack of alternatives or family resources. The other choice was made by my grandfather as he matured, married, and had children. That choice was undoubtedly difficult for him, yet was based on his experiences, times and insight for the future. It was his choice not to tell anyone about his sister - to keep the secret of Maggie, her problems and her institutionalization. His weekly trips (to an institution unknown to us) were actually to see her. This must have been difficult for him keeping this secret, maybe feeling guilty, but not knowing what else to do. The choice he made affected the rest of his life, the life Maggie has, and even us today. Some members of my family feel they should respect his choice and his wishes - which means not acknowledging Maggie or going to see her. She is still alive - having survived in an institution (nursing home) since 1926. Again, it's a choice made that has changed the course of lifetimes along the way.

Now it's time to make another choice - one that seems very obvious - to go to her, visit her, and see

her. But, it's a choice my family finds difficult based on the past. Sometimes we don't make the "right" choices, but it's another funny thing about choices - we can always make new and different ones. They may be uncomfortable or unsettling, but they always open up new doors. For me - it's a new chance to meet the last older living member of my family. Choices are not always easy, but choices are really opportunities to experience new things and grow. They're based on past, but do influence the future.

So, choice - the power word - a word that makes us think about what we do and who we are. Choices are powerful for all of us - by providing opportunities, chances to influence our lives. I suppose for many of the people we support choices are often limited, just as they can be for us. Overall, it often times takes just one event for us to see how choices were there when we didn't see them, or ways to *create* new situations or choices for ourselves. It's a power word - one that involves personal power, and a process that can influence lives forever - and most definitely not one to be taken lightly.

October 1989 –Theresa Fishler

Faded Photographs

Until three weeks ago, my 94 year old grandfather and 89 year old grandmother had managed to stay in their own home, despite blindness, crippling arthritis and other health problems related to their advancing ages. They stubbornly refused to make significant changes in their lifestyle until the crisis our family had feared finally occurred: my grandfather fell during the night and broke his hip. Literally overnight their lives were transformed. My grandfather was taken to the hospital where he underwent hip replacement surgery. Though his body was repaired, his sharp wit and quick humor were lost to confusion and despair. My grandmother was taken to a nursing home where, alone, she was forced to face the loss of autonomy and control many older people fear.

This past weekend their four sons along with their wives and a few grandchildren tackled the difficult and painful task of deciding what to do with the possessions these two people had accumulated throughout the sixty eight years of their marriage. My grandparents were not wealthy people. Most of their lives were spent on a small farm in southern Minnesota. The only place for many of their things was the dumpster parked in the driveway. Many others were marked and set aside for an upcoming garage sale. The pieces of antique furniture and china of value were divided among the four families according to my grandmother's wishes.

Sorting through their things did occasionally unearth a treasure of inestimable value, however: the drawer that contained my grandmother's wedding veil, shoes and silk ring bearer's pillow, the trunk that revealed baby clothes and shoes worn by my father and his brothers, the box holding strands of hair from my grandmother's first haircut and the rusted bucket in the basement that held metal cars and trucks, toys the four boys had shared. The day was almost over though, we were gearing up to leave when we found the greatest treasure of all. Several boxes of old photographs, keeping the vacuum cleaner company in the coat closet. Moments of a family's history frozen in time.

A picture is worth a thousand words. The power of this statement was quickly realized as we all gathered around the boxes, alternately shouting with delight and laughing hysterically as the pictures were pulled out one-by-one and passed around. There was my grandmother as a child of three with her brother and again, as a young bride. My grandfather, young and handsome graduating from high school. My father and his brothers as babies and young men. Myself as a chubby nine month old. It was the perfect end to a long, difficult day. We prepared to depart, many of us in different directions feeling happy and complete somehow. The pictures had brought us together and given a sense of meaning to the painful decisions we had made that day. We were a family.

As I tossed in bed that night and reviewed the day's events, my thoughts often turned to those pictures. Now that I'm soon to become a mother I often think about my own child to be and how I

will create a sense of family and belonging for her or him. Those pictures seem to be an important part of that. I also thought about people I know who have lost their history, who have no pictures or even people to tie them to the past and to their own creation. I recently had a conversation with Ann in which she explained that she has been helping Carol to remember and record her personal history. A history punctuated with institutionalization and loss of control. A history devoid of family and memories captured on film. Carol has no pictures of herself as a child or of her mother as a young woman. Ann explained that she was planning to investigate what happened to Carol's mother. As Carol's friend, Ann was trying to replace a piece of the history that she had lost.

I also thought about Darwin and the power that a single picture held for him. He, too, has experienced a life of institutionalization, separated from his family. Unlike Carol, however, Darwin has memories of his mother and knows that she is dead. He sometimes crosses his hand over his throat and points upward to indicate that he's thinking about her. A couple of years ago Alice gave Darwin one of the nicest gifts he has ever received. She tracked down a cousin of Darwin's who cared enough about Darwin's need to connect with his past to locate a picture of his mother for him. Darwin was thrilled to be presented with this treasure and insisted that her picture be immediately cut to size and pasted on his communication board! Darwin finally had a precious faded photograph and he couldn't wait to share it with the world.

February 1991 —Julie Nichols-Younes

111

On Why I Do This Work

Aren't You Ever In Danger

"Where are you working now?" my dentist asks while preparing to examine my teeth.

In the past I've said teaching high school and running a bait shop. Both responses were met with some understanding and some interest.

"I'm working for a non-profit agency providing support to people with developmental disabilities who live in their homes."

"Do you like that?"

"Yes, very much."

"You go to their homes then?"

"Yes."

"Aren't you ever in danger when those retards get violent?"

I answer the question carefully, like something is dependent on my reply, talking about individuals I know who are gentle and fun to be with. I talk about institutions and a community that knows only stereotypes of people with disabilities because they have been separated from us and locked away. I say I have never felt threatened or in danger in my work. I say that his perception is understandable but it is not accurate. It is the summation of fairy tales and stereotypes and human fears.

I see Barb and Tom posing for pictures after their wedding.

I think about Alice fighting with all her being to keep control of her life.

I remember David saying, "I am a case. I was born with brain damage and locked in an institution for many years."

Cathy lays curled in a ball on the table of the CT scanner. "I want to go home," she sings over and over in a sad slow whine.

"You can do this. Think about the music. You can do this," I sing back. She uncurls, her body shaking all over. Slowly she begins to breathe in and out and a very slight smile crosses her face.

Sally says, "I wear diapers sometimes. Do you wear diapers?"

Others say, "She's a real strange one. She wears diapers and eats baby food."

Sally says, "At [the institution] they put people in big strollers and cribs. Why?"

Others say, "You don't need those diapers. You're an adult."

Sally says, "I'm going to rip that diaper off that baby. What will her mother do?"

Others say, "Diapers help her feel safe."

Sally says, "They wrapped me in tape when I was violent.

I wonder, "What does it do to someone to be wrapped in tape?"

Tom used to spend most of his time staring out a window in his living room and his life was a series of medical appointments and therapies. His attendants burned out with his constant demands and orders. His life changed because he got a job he liked. At this job he met a woman who fell in love with him and he with her. He moved to an apartment in a neighborhood where he became a member and a friend. All the rest followed.

Alice was the first person I met with a developmental disability. She turned out to be one of my greatest teachers. She pushed me to places where I had to face my fears, examine my beliefs, define truth, and understand love. She was monumental in my life and she taught me about death.

I've been wandering around all week trying to sort through why I do this work, why I really do it.

Maybe I do it for myself, because it meets my needs and makes me feel alive. People with disabilities and the people they know have helped me to look beyond my own experiences, to learn other realities, other possibilities, other truths. I value being able to do something that touches that part of me I call my soul. I have never felt so happy or so scared or so sad or so angry as I have doing this work. I have never been so lost, so confused or so filled with energy and insight. I fell into this work by accident. I had no plans to be here. But it feels like I've stumbled upon life's very essence... people's pain, their joy, and survival. It's like nothing I've ever known and at the same time it's a reflection of my pain, my joy, and my survival.

November 1990 –Kathy Lemke

More Than Words

Do we know where we are? If so, do we know how we got here? If so, do we know why we came? If so, do we know where we go from here? I'm asking myself these questions about my work, and the "mission" and "vision" of Options. I start asking these questions more when my stress level begins to increase... I take that stress as one of those early warning signs that something is not right. The not right part may be what I'm doing, how I'm doing it, or what I am not doing. It might be that I've forgotten why I'm doing it.

Have I lost my focus? Have I lost track of why we do what we do? Is what Options professes to stand for—those three values that we speak of so righteously to other providers, really guiding us? Can we really pull it off? Are we supporting people well? Are we supporting people the way they want and need to be supported?

There are some big questions about how to best support people being debated on our team right now. One of the questions is about how we have supported an individual over the last few years, and if we have done the right thing, and whether we should continue to support her, or if our support is the cause of problems she is currently experiencing. Should a different agency be supporting her? Would it be better for her?

Another question is about what our role should be in implementing a fairly controlling, behaviorally based, restrictive, manipulative, punitive plan designed to help somebody be more like we wish he was. I know it sounds from the description like we shouldn't do it. But what ***should*** we do? Even when we can clearly identify that the problems a person is having are due to environmental stuff, what do we do? We say "individualize", build supports around the person, be flexible. Alas, easier said than done.

I know that the discussion and debate is important. It helps us stay focused on why we are doing what we do—and what it means, on a day-to-day basis to provide support based on those values, which lead us toward our vision of community and acceptance.

I still have all the same questions. I don't know what is best, and I know that I personally have been known to make a mistake or two. I wonder if the fact that so many people we support are having some fairly rocky times in their lives is because of our support, or in spite of our support. Are we doing the right thing? I don't know, but I'm sure we are doing the best we can.

Those values: that everyone has a right to live in their own home, where they choose and with whom they choose; that there is nobody who is "not ready" or who is too challenging; that we are committed to be with them over time; that everyone has a right to control their own life; and that people have a right to participate in everyday community life. They are more than words—they are things I believe in.

March 1990 –Kim Turner

Growing Up at Options

Last year, 1989, when we were doing my performance evaluation Gail mentioned that I was no longer the new kid on the block. She talked about my role as a support person for my coworkers and as a voice in the agency. Although I knew I had been at Options for almost five years I hadn't really stopped to think about my longevity and its relationship to the agency. For once I had held a job for more than two years. Finally I was not in a position that was just a job to make money to pay for the schooling that would turn me into a professional. I finally *was* that professional.

Being labelled a professional and being Amy Lutzke has always seemed somewhat incongruous to me. Part of that I am sure has come from the mystique of just what a professional was that has surrounded most of my working life. My family consists of laborers - farmers, factory workers and construction workers. There was not a lawyer, doctor or so-so worker in the bunch until my generation.

Going to college and becoming a professional was something I found myself aspiring to upon completion of high school, even though I had little idea of what I was getting into. I always had jobs where there was a boss and there were employees. The boss told us what to do, we complained about it and then we did it. As far as I knew that was work and that was how it was supposed to be.

The trouble started as far back as when I was student teaching. People wanted me to think about what I was doing, they wanted my ideas, they wanted *me* to make decisions. So... I made monumental decisions about what student I would write a behavior modification program about, in what order the students would have toothbrushing lessons after lunch, and why.

When I graduated I decided that I had learned enough to know that I didn't know anything. I was sure, however, that there would be a boss out there happy to tell me what to do so I could go off and do it.

Enter [a supported employment program]. Though that program threw me into the midst of major professional responsibility there was no supervision or guidance to go with it. The fact of the matter was that I *didn't* know what I was doing and neither did anyone else there. In feeling our own personal failure and disillusionment, my coworkers and I withdrew into ourselves until we could no longer function as an agency while our director marched on proclaiming a success that didn't exist.

By the time I came here I was very unsure of myself and my vocation. Fortunately, here is where I ended up. Here I was given a case load of responsibility along with a team of support. Of course this new configuration took some getting used to. I still felt most comfortable just checking things out with my "boss" and then going to do them. It took me a couple of years to participate more with my team, but it took me until this past year to finally find that mysterious professional within myself.

You see, my team is not particularly willing to tell me what to do. They will listen, they will suggest, they will relate, they will support, they will confer, they will facilitate, they will encourage and they will congratulate. I have to make the decision.

Being weaned abruptly from having someone in charge to check things out with and get a final OK was a great growing experience for me. I don't really know the words to say how I'm different, it's more of a feeling. It is a feeling I have sensed throughout Options.

There has been a lot of individual and agency growth here. We have begun to share a sense of wholeness. We have all been faced with the individual job of finding the answer but I think we have collectively come to realize that there are no answers, there is us. Together we will work it out, we will stick it out.

June 1990 —Amy Lutzke

The People Here Fill Me Up

What is it that has kept me here for the last six years?

The money? Well, we all know about the money. I'll just say, that once I'd like to see a pay check as big as my Visa bill. And after spending the weekend writing summaries and this story, I can assure you it is not the paperwork that keeps me here. That's enough to make anyone run for the hills. You know, I've often wondered what's on the other side of those hills. It must be lots of money and nothing to write with.

But in thinking about what really keeps me here. It's not just the obvious things like philosophy, values, atmosphere, vacation time, and getting sympathy for being poor. What really keeps me here is the people. I've formed some significant relationships with staff and the people I support. I get something different from every one of those relationships. They fill me up. And it's that more than anything else that keeps me coming back every Monday.

November 1990 –Diane Steele

Options Treats Its Employees the Same Way as the People It Serves

I have been doing this work for a while, and the first reason why I am still here at Options doing it is because Options took a chance on me. I hadn't held a "regular" job in a long time, and although I had experience, I had no formal training related to this job. I am staying partly out of loyalty because Options gave me the opportunity to prove I could do a good job.

Opportunities are another reason why I'm here. Options continues to offer me many opportunities to take on new projects, learn new things, and meet new challenges.

Options itself is a challenge - to the status quo. Its goal of empowering people who have had few choices in their lives is one that I feel proud to support. I would rather spend my energy on Options than on most profit-making ventures.

However, profit is also a motive: Options has always shared its resources among *all* staff. In this way, as well as in others, I am treated as an equal. This is different from many work places, where people in positions like mine become extensions of machines, and sometimes even extensions of other people, places where equality is not the rule.

Equality is important to me. One reason I stay at Options has to do with decent treatment: the lack of harassment and more importantly, the open atmosphere where workers can speak their minds. Although it may be frightening to do so here, speaking your mind can be cause for dismissal in other places. However, this openness sometimes makes the process of decision-making at Options frustrating to me. I am used to having decisions handed down from above, a method which has its advantages. But, the results at Options speak persuasively for the far greater advantages of consensus, no matter how hard won.

Along with consensus goes support: for example, Options' attitude toward employee benefits allowed me to use sick time for my children, again unheard of in many work places. This enabled me to keep my job and raise my children at the same time. For me, this is one of the most valuable reasons for staying.

When I look at all these reasons added together I see the one real reason why I am still here: Options treats its employees the same way it treats the people it serves, as equally valuable human beings, deserving respect, consideration, and trust.

November 1990 –Polly Molenaar

Jenell Dale

Bert Hollis

Don Jean

Kathy James

I was tempted to end my story here but I realized I was asking everyone to find a list of names - both an obvious response and a self-sufficient reason for continued work at Options.

This job calls on all of my being and makes me reach for more than I knew I could accomplish. I ask you, where else would you be called on to be a doctor, lawyer, beggar-man, chief, not to mention plumber, accountant and comic relief?

I work at breaking up old habits. I strive to become aware and cast aside long held concepts that impair my ability to respond in a real and effective manner. To manage to reach for a more honest and workable interaction in my job requires the talents and insights of the team I am a part of. The team trues me (and each other) up and helps me make real responses to an ever changing terrain.

Working at Options is living and breathing in a constantly vitalized and challenging environment. Each day has new wings on its feet - and me without a pilot's license.

I am not bored. Scared sometimes, down sometimes (can't always break those old expectation habits), confused often, but never bored.

I'm here - today has new wings on its feet.

November 1990 –Ellen Backus

Tedious, Messy, & Mundane Things That Really Make a Difference

This isn't the first time that I've asked myself why I'm doing this work. I'm sure most of you have asked yourselves the same question in a rhetorical way on various occasions. Those kinds of days when nothing seems worth the grief, the pain, the mess. What am I doing this for? I don't need to describe it, you know what I mean. This is the first time, though, that I've had to actually answer that question in a concrete and meaningful way. I was surprised to find that the answer was harder to reach than I thought it would be.

I do know why I don't do this work. I don't do this work to get rich and improve my status. We all know that human service workers are underpaid and devalued. If money and status were our most valued job characteristics none of us would be here.

I don't do this work because I'm such a special, unique and altruistic individual. I hate it when people imply that you must be endowed with nearly saint-like qualities to do this kind of work, as if to imply the people we work with are so awful, only a saint could stand to be with them. I don't feel any more special than my mail carrier, the clerk at the corner grocery store or the neighborhood crossing guard. I'm just an ordinary person doing my job.

I really don't do this work because it's so "rewarding" or because "I get so much out of it" as some people might imply. Cleaning Carol's filthy apartment, balancing numerous checkbooks, wasting away hours in doctor's offices, writing annual summaries, and grocery shopping are just a few of the many aspects of my job that are more tedious than fulfilling.

Sometimes I ask myself, "What would I want to be doing if I wasn't working at Options?" The answer is always emptiness, a blank space. Somehow, nothing else seems right. I think it has to do with the purpose and the meaningfulness of work beyond simply making money. Would I find meaning in selling appliances at American T.V., selling real estate or insurance, or selling anything for that matter? I doubt it. What we do is meaningful because it really matters to the people we support. Their lives would probably be drastically different if we weren't here doing what we do.

The tedious, messy and mundane things that we do are meaningful because they really make a difference in the quality of life of the people we support. I could work for a cleaning service to clean apartments, a bank to balance accounts or a clinic to spend time in doctor's offices, but doing these and other things as a whole at Options has a larger purpose and meaning that transcends the individual and sometimes mundane things that I do. That is why I do this work.

November 1990 –Julie Nichols-Younes

The Most Fast-Paced, Deadline Oriented Job

Every once in a while one of you will say to me, "It must be hard to sit at that desk all day - never a change of scenery." But I think Polly and I have the most fast-paced, deadline oriented job in the agency.

The phone certainly always rings and many of the calls are predictable: Ron always trying to reach someone once more, Barb with one more thing to say, Cherie with one more emergency item for her shopping list, one more dentist with an appointment reminder. But there are also calls from California and Texas asking for information, from clients who really need help right now, from the police on occasion, and from neighbors with angers or concerns. It's a rare day when the calls are really "all the same".

It's taken a couple years but the spreadsheets for quarter hours, MA billing, benefit hours, and respite hours are finally becoming old friends instead of prickly new acquaintances. I'm beginning to understand the payroll, the general ledger, even month end processing (now that I've written TURN THE PAGE in the direction book). Polly's comment of, "I've got a whole new idea for that spreadsheet next year," means that things will change, and that bit of change, that need to stretch just a bit more to really understand, keeps the job from being boring.

This past summer my mother, my aunt and I drove to Door County. We visited with an aunt and uncle I don't see very often and they were full of questions about my fulltime job, what I did, and how I liked it. My Madison aunt sat up in her chair, looked at me with total pride, and said, "Why she even speaks at people's funerals!" I turned and looked at my aunt and uncle with their totally blank faces, mouths slightly open, eyebrows raised, and what could I say? I simply shrugged and said, "It's not like any other job I've ever had. I think I'll stay there awhile."

November 1990 –Carol Lofgren

I Know, Because I Have Been There

I guess it all gets down to what I really believe in. That people are what's really important - and in the big scheme of things, what else really matters as much? Yeah - that's what keeps me going. I have tried a lot of different things, but have never walked away from those jobs feeling the way that I do now. This type of work seems very natural and good for me. I really feel like I am doing something worthwhile. I mean, I know what a struggle it can be at times to just get the basics, like how do I get to the grocery store to get the food I need, and what do I do if I don't have enough money to pay the electric and phone bills, and where do I go to look for a job? I know, because I have been there. And wouldn't it be nice if all these things were in place, so I would have more time to get more pleasure out of life? If I can make life at all easier or nicer for someone, then that makes it all worth it. And I know for myself when I feel like I have control over my life, and when I have autonomy and sense of self, and when I am doing the things I like doing the best, then that's when I feel the best about my life. And I believe that everyone has the right to that. And I also want to live where I want to live, and do what I want to do. And I believe everyone has the right to that, too. And the world is not set up so that people can conveniently do this, so where I can help out, I will. And I

have to admit, that a big part of what keeps me going is my anger. I am angry at society for wanting to make everyone the same, and for wanting everyone to fit into the "perfect mold" and to live up to society's values. And that anyone who doesn't fit into a certain role is thought of as "less than". And a big part of that comes from my experiences as being a gay man, and the situations that I do face in society that do not validate me or my lifestyle. I do know what it is like to be thought of as "less than" and I have struggled with just affirming my sense of worth as a human being. So I have developed empathy for others and this has renewed my commitment to helping others. And it has been a combination of experiences in my life that has helped me to develop insight and awareness, and to help me reestablish my values and to help me see more clearly "the big picture". My role as a "caretaker" in my home growing up, has given me some skills in helping others, and now I can do that in a very healthy and worthwhile way. And that makes me feel very good. I get a lot of satisfaction from it. But most important of what I have learned, and it really is very simple, "Treat others like how you would like to be treated." With the dignity and respect they deserve.

November 1990 –Timothy Boylan

People's Lives Are Chaotic & Mysterious

I'm writing about something I've given a lot of thought to over the years. Several times a week, in fact. Why am I doing what I'm doing?

I'm doing what I'm doing because it's fun enough and exciting enough to make me want to keep doing it. It's vitally important to me that I like my job, at least most of the time. It's important to me that my job fit the rhythm of my life, on a practical as well as philosophical level. My job is not the most important thing in my life; but it is a big part of my life, and can not be separated completely from the rest of my life. I need for my job to be that way. And I need my job to allow me to put my energy toward a constructive end.

Almost every reason that I like my job is a selfish one. This would sound odd to some, since my salary is relatively low. But while my work to some extent may improve the lives of others, it also improves the life of me. In my job I give and I take. Every day, I learn from people around me all kinds of things about living. I don't think I'd experience that if I were selling water heaters.

There are things that discourage me about my job. Options is a service agency in a service system and I'm a service worker and we're here to serve people. Usually we serve people well. But I have nagging thoughts that at some times with some people the service we provide is a disservice. Occasionally this makes me think I should not do this anymore. At particularly stressful periods in my job I mentally write a resignation letter. But the low points make the high points higher. And I'm lucky, because I have more mountains than valleys in my job.

I get to meet all kinds of people who apply for jobs, people who are ordinary, extraordinary, bizarre, wonderful. I see respite workers doing demanding work for little pay. I see people we support put up with crazy schedules of in-home workers during periods of chaos and confusion and still keep a positive attitude. And the stories I get to hear —sometimes the stories themselves keep me going. I have supportive, creative, friendly co-workers. I never feel isolated.

I'll never feel completely in control of my job. I won't be able to prevent the chaos. I'm dealing with unpredictability. We all are. We're involved in the lives of people, and people's lives are chaotic and mysterious and far from predictable.

I'm glad that at this point I like my job. I mean, what else am I going to do? Be an investment banker? Be a chemical engineer for Texaco? Yeah, right. Someday I'll take a different direction with my job. But right now, I'm lucky that 9 days out of 10, I look forward to coming to work in the morning.

November 1990 –Peter Bazur-Leidy

On Writing Stories at Work

Story writing at work is unusual. At a conference presentation in which Options staff, including the director, read stories they have written, a listener asked, "What does your director think about you taking work time to write stories?"

Writing Stories

When I was in eighth grade, I had a rebel social studies teacher, Mr. Corrigan, who made us write every day for a class assignment. We could write anything and we never had to share what we wrote with the class. But on every paper I handed in, he typed his comments: words of encouragement, insights, affirmation. That year I discovered my inner person. For the first time I felt my thoughts and feelings were important. There was more to me than a kid who was trying to impress her friends and fought with her parents.

A few years ago some of us were talking about feeling disconnected from the meaning of our work at Options. It was hard not to get caught up in the day to day struggles. It was hard to maintain and deepen our connections to each other. We came up with the idea of story assignments for staff meetings.

People were not thrilled with the idea. To say there was "resistance" is putting it mildly. But from the first time we read our stories, there was a change in the energy of the room. We could all feel it. We started out with stories at the beginning of the meetings. It didn't work. We often were so affected by the stories that we couldn't move on to regular business. So we moved them to the end. They've always been the best part of our meetings. In the last three years we've laughed and cried together, shared our most intimate thoughts. Somehow we take more risks in writing than in talking.

The stories connect me with why I'm here. They make the mission of Options real for me. The stories deepen my understanding of the struggles and the joys of our work and of the lives of people with disabilities. The stories help me see people I have known for years in a new way. The stories create a space for me to step back and to reflect. The stories take down the walls between us. They sort of take me back to the center and ground me. Every time I do a presentation I read stories beforehand. They give me courage and they remind me to stay focussed on the heart of this work.

July 1991 –Gail Jacob

Memories Fade...

> "My stories... are the windows on the house in which I live, yet I seem to be able to see through only one window at any time. Although I may erroneously think that what I see is all there is, I can actually see only a small part of what is in the house. If I look through another window, I see something entirely different."
>
> –A. R. Beisser. *A Graceful Passage - Notes on the Freedom to Live or Die*

All of the stories are powerful to me. When I hear them read, I hear about a part of our work and lives that I would otherwise not have much access to. Reading stories to people outside of Options is also very powerful - the stories seem to touch people in a way that hours of talking about what Options is about can't. I like to re-read stories when I'm struggling with my work. I sit in the library and page through the book. Sometimes I read bits of lots of stories. Sometimes I read all of the stories written by one person.

As I remember it, we started writing the stories because we wanted to be better able to tell the stories of the people we supported. Not the official history contained in green files, but the real story about who a person is. Noam Chomsky said, "Memories fade, and only official history remains." The stories are a challenge to that. They are a way of recording a moment of truth that

would not usually find its way into official history. The stories become the unofficial, unauthorized, unabridged version of small moments in our collective experience. They will remain when our memories fade.

Without the stories, would I remember Darwin's tears when seeing himself on TV, the birth of MO's nephew, the experience a student had with Roger, Diane's opinions on clinic waiting rooms, Sid's clever analogies, and all of the joys and fears of the last four years? Not with my memory. And who wants to have only "official history" to remember? Not me.

I never let writing stories be an ordeal. I only write them when the pen keeps moving on the paper. When it stops, I stop. The quality of the words written is not my concern. I write what is on my mind and have some desire to think through. Other people talk of their struggle to get their pen to move. Aren't individual differences wonderful?

This leads me to a final thought. I would guess that we have probably written around 400 stories. I have experienced the whole range of emotions in hearing them read - tears, tension almost too strong to bear, laughter that made me ache, fellowship, fear and wonder at the world. I have felt angry and offended by both the experiences described, and by the message of the writer. But I have never heard a story which wasn't compelling and important in some way.

The stories will not write themselves, but they need to be written. Without them, our shared experience is less rich.

"Without such story windows, I could not see much meaning in my house at all, so I am very grateful for them."
–A.R. Beisser, *A Graceful Passage*

July 1991 –Kim Turner

A Little Bit of Myself

I sat and reflected on the past couple of weeks. I was trying, with great difficulty, to come up with something positive for a story. I went through my entire caseload twice and came up empty. Everyone has been having their moments - none of them Kodak.

In rehashing everyone's moments for the millionth time, I realized that there was something positive about every situation. After returning to the office, I would share the story, receiving words of encouragement and understanding, a pat on the back and some lightheartedness, a feeling of tomorrow really is another day.

The people responsible for these positive moments are my team mates. They often hassle me about my lack of self-disclosure. They tell me I'm somewhat of a mystery. Well, I'm going to let a little bit of myself show through right now. I care about all of you a great deal and am thankful I have you to come back to and keep me grounded.

November 1989 –Diane Steele

What Writing Stories Does for Me

When I first heard about the story assignment, I thought, "Oh, no! Not one of my strongest traits - writing!" But after hearing many of the stories, during the first few All Staffs, I got encouraged to give it a try. For me, it was such a neat way to learn about other people, the people we support, and the people here in the agency. The many interesting scenarios, and anecdotes, made me stop and think more about the type of work that I do. I always find it interesting to find out more about someone else's philosophy on life or the approach and attitude they might take to their work. It gives me more insight into who they are, and helps me to see things in a different perspective, one

that I might not have thought of before. And I really need that, it encourages me to stop and reflect, and think more about the type of work that I do. Otherwise I don't know if I would always take the time. Sometimes I feel like I get caught up in the daily routines and I lose sight of the fact of why I do what I do. So it helps me to slow down and take the time to think about what I am doing.

So now that I have written a few stories, I'm finding it easier to get motivated to sit down and write. Even as I write, I think more about why I am here, and what I am doing. And I really do kind of like it, I mean where else could we go, and it would be part of the job, to write about the people we support or the work that we do. I see it as a real benefit, to inspire me and to keep me going, and to give me insight into how I can do my work better. And each time that I hear the stories, I go away with some new food for thought, more things to ponder, and a little bit more knowledge about the people Options supports, and the people that I work with.

July 1991 –Timothy Boylan

Story writing is as much work for Options staff members as for any other writer

SWS

'Twas the night before All Staff, and all through my mind
I searched for a story that I could not find.
"What have I to say?" I wondered out loud
"That's not been said by someone else in the crowd?"

So I sat and I thought, and I thought and I sat
And what came to mind but a ball and a bat?
But no, someone else could surely explain
How Bar & Grill Options won their very first game.

As I stared at the page and the silence grew louder
I developed a craving for a bucket of chowder.
So I called up Gretchen, but she wasn't home
But I figured I might as well stay on the phone.

I dialed up mom, I dialed up Dad
And told them I needed a story real bad.
"No," they responded, right on cue
"We're not gonna do your homework for you!"

So I doodled and doodled and doodled some more
'Til my doodler refused to work any more.
My head was aching, my eyes were red,
So I gave up all hope, and trudged off to bed.

There I lay sleeping deeply, for hours it seemed
And got lost in a rather delightful dream.
The way it proceeded was pleasant and funny
For my dream was about Options' extra money.

Seems Polly came up with some more underspending
And our faces erupted with smiles unending.
For unlike the days when our budget was tighter
The time had now come to hire a writer.

BEST COPY AVAILABLE

Story Writing Specialist the position was named,
And for wanting this person we shouldn't be blamed.
So now no more worries of nothing to write
Or fretting and panicking late Monday night.

Now we'll walk into All Staff each month to meet
And settle, each one of us, into a seat.
Sit back and relax, a big happy bunch
While our newest staff member reads us stories at lunch.

July 1989 –Peter Bazur-Leidy

Writer's Block

Yesterday morning I sat down to write a story. I had plenty of time and was eager to write something moving or at least memorable. With a fresh pad of sunny yellow paper and newly sharpened pencil in hand I sat down at my desk to "create". I sat at my desk and stared at that blank sheet of paper for a while. I stared and I stared but no words materialized on the page. I moved to another chair near the window hoping that the change of scenery would spark a creative spurt, but still I stared. I tried a variety of diversionary tactics; going to the bathroom, eating my lunch (early), filing my nails, but it soon seemed hopeless. The blank page was becoming a fuzzy, yellow blur. Finally, I gave up and busied myself with other tasks.

Late in the afternoon I came back to my Rowley-Schlimgen No. M9-20220 yellow legal pad and Eberhard Faber Marigold 240 No. 2 pencil hoping to break the spell at last. I was beginning to feel desperate knowing that I had only an hour of phone duty left in which to complete a tantalizing tale, an amusing anecdote or nostalgic narrative with which to entertain my colleagues. If I didn't meet this deadline I knew I would be forced to drag that terrifying yellow pad home with me to be stared at upon my coffee table all night. I was horrified by the thought. I was equally mortified, however, by the thought of appearing at the All Staff empty handed. The shame of public humiliation was more than I could bear! I was reminded of a dream I had a few months ago in which I came to an All Staff without a story only to find John O'Brien waiting eagerly to hear it!

As the clock ticked on and I became more desperate, my thinking also became more delusional. I began to consider any possible alternative to penning an original composition. I could read an excerpt from Reader's Digest, I could throw myself in front of a speeding truck on East Washington Avenue, or I could pretend to pass out when it was my turn to recite.

I was just putting the finishing touches on a letter of resignation when the idea struck me (it was 5:50) I would write a story about writing a story. It was a novel concept, never before attempted in our year-long story writing odyssey. I quickly put pen to paper and began at last to write. So, here it is my friends, a story about writing a story, or not writing a story as you may choose to look at it. I breathed a huge sigh of relief as I called the answering service and shut down the office for the night. However, as I turned off the lights and made my way to my car a nagging question began to gnaw at the recesses of my mind. "What will I write about next time?"

November 1988 –Julie Nichols-Younes

What Happens When You Don't Write Stories

People by nature are predisposed to storytelling. We love to have stories read to us, told to us. We love to read stories and tell them, create them, collect them and recognize them when they unfold. With an appreciation for life and the human spirit often comes the joy of channeling other people's stories you have been exposed to.

I have given a lot of thought to how the oral/written tradition helps mediate reality. It is sort of an existential matter for me. Though I haven't written many stories at Options I am not new to stories nor to human service work. There have been many times in my work when I have felt the frustration of not having the time or the forum to share or have shared with me some of the stories all of us gather from people we work with and from our shared experiences with them.

These stories, the stories of people's lives and the connection to ourselves are at the heart of the work we do. Telling stories is a return to what is natural for people to do. Not sharing the essence of our work is the outcome of our overly sophisticated, fragmented society in which we are rushing around doing tasks and often forgetting why. Writing stories reminds us of the soul of our work.

Since so much of our work involves experiencing other people, if we don't write and reflect on our experiences we lose the opportunity to process them. If we keep these stories in our heads many of them fade from memory after awhile. If we write them down we can hang on to them longer. If we write them down and have no place to bring them beyond the paper we've written them on we lose out on an opportunity to communicate with others. When we don't communicate with others we tend to isolate. When we don't reflect on our experiences we tend to lose our focus.

During my work as a substance abuse counselor one of the people I was assigned to work with drowned. I grieved intensely. The only thing that helped me was taking a pad and pen and sitting by the apartment where he had lived and compiling a dictionary of Howeisms. The guy had his own delightful expressions he'd infuse every conversation with. I can still pull out my dictionary and can share it with others who knew him.

Aside from having someone from the Mental Health Center come and diffuse our feelings it would have been so simple for us all to write down some of our thoughts, feelings, experiences around Phil and that would have probably had a powerful healing effect. It is amazing how hard it is to think of simple solutions sometimes.

Though I haven't written many stories at Options thus far and though these assignments take me way too long, I very much appreciate the opportunity to take the time to process my work, to hear about what my co-worker down the hall experiences and feels about what s/he is doing. It promotes a sense of belonging, a sense of agency identity and I think would be beneficial for everyone to practice who works in our field.

Certainly an added benefit to writing stories is to share positive stories about people with disabilities with a wider audience of people who know little about the subject. The power of a story can help create a person's value system or transform a prejudicial value system.

July 1991 –Kathy Shenker

Reflections on Story Writing at Options

1. Writing stories is an exercise in self-disclosure. The authors take risks in writing about their own lives, as well as their relationships. Many stories are very personal and intimate. A safe place and an encouraging audience are essential for sharing the stories. Both the writing and reading of the stories seems to get perfected over time, with practice. Story writing has been a learning, growing experience for everyone.

2. The stories reflect the blending of professional and personal relationships. Roles are more blurred, and the boundaries between staff and the people we support are less evident. The stories place us all on the same plane. Stories have a way of bringing staff or the people who read and share the stories closer together.

3. "A picture paints a thousand words"— like the phrase — the stories "paint a picture." Whether I know the person or not, listening to other people's stories creates a visual image for me.

156

BEST COPY AVAILABLE

4. The stories elicit a gamut of emotions — both for the writer and the audience. The stories are happy, sad, funny, serious, informative, silly… and above all, an honest and caring reflection on our relationships.

5. Story writing does not necessarily require specific skills or talent at writing. They generally come from the heart, not the mind. They are softer, much more personal than required writing —such as annual summaries, assessments, forms, log notes. It's important that the stories are self-generating and not an "assignment." The stories lose their flavor, and don't feel the same if they are required, formal, or written for someone other than ourselves.

July, 1991 –Alice Sosinsky

Stories Build Community

Whenever we tell a person's story, we take that respect and add validity to it. Stories are the way human beings recognize experiences, give names to feelings, celebrate perceptions of the world. In a very real sense, there is no experience without stories. Stories give shape to experience. Experiences give rise to stories. Each time we meet a new person we spend the beginning of our relationship telling our stories.

For persons with a disability most often their experiences, feelings, and perceptions are not related in stories either because they can not tell their own story, or if they can, others are not listening. When we take on the role of their storyteller and we do it with respect for them, we give validity to their experiences, their feelings, their perceptions of the world.

For these reasons and more, we must continue to write people's stories. They give us practice in being good storytellers. They give us an opportunity to step back from our day-to-day work and examine the vision and our understanding of it. They raise our comfort level in talking about people with disabilities in the community. They raise community awareness and dispel stereotypes. They allow communities a conventional tool for seeing people with disabilities as individuals. They spread the vision we want for people.

January, 1990 –Kathy Lemke

Stories from Beyond

Well, here it is, 7 p.m. the day before a story assignment is due and me without my story. This has happened on more than one occasion in the past three years of relating my experiences at Options through prose. Most of the time I manage to throw something together and usually it can be called a story.

Most of my stories tend to feel kind of formal to me. They generally have a beginning, a middle, an end. A lot of the time I feel frustrated that the ideas or feelings I'm having are not translating well into the written word. I think that comes from not being real comfortable with my writing style and not being used to expressing myself through this medium. It also is sometimes the result of not taking the time to write down the story when it happens but waiting until 7 p.m. the day before a story is due and then trying to recapture the moment.

One of the stories that I wrote here at Options had a profound effect on me and is one of the reasons I keep writing these things even though I'm not always happy with the results. It was one of the few truly psychic experiences that I have had in my life. Those of you who were here may remember the story, more from my inability to read it, than from what it said. It was the story about a baby born with a disability in the 1940's who ended up being institutionalized. If I remember correctly Gail finished reading it for me.

I wrote this story shortly after helping Terry move from [the institution] to Madison. I had visited Terry a few times at [the institution]. The first time I went alone. I didn't realize at the time that there was an old [institution] and a new [institution]. The old buildings sat atop a beautiful oak studded hill. They were three stories high, rectangular, red brick, wire mesh covering the second and third story windows. It seemed a little empty on the driveway but I couldn't see the modern new cottages tucked down along the sides of the hill from where I was so I parked my car and walked up to the nearest building.

I didn't really have to get up the steps to realize that the lovely green (you know the green) interior was empty. But I think it was in those moments, standing on the steps, gazing in the window that that story came to me.

People asked me later if it was Terry's story but I don't think so, too many of the details didn't fit. I don't know if it was one person's story or hundreds, I just know it wasn't my story. Shortly after my visit full paragraphs would pop into my head. It wasn't just a thought or an idea but the real words, like somebody was dictating to me. Over the next few months the pieces kept coming to me until I finally sat down and wrote them on paper. I tried to add stuff of my own but it came out kind of garbled. I bet if you read the story now you could pick out what I added from what was given to me. I hate to sound like Jean Dixon in the National Enquirer but it was almost like the automatic writing that some psychics describe doing.

So in this story of writing the story I guess I just wanted to share this experience. It was an experience of receiving the energy from souls who may otherwise never have been heard and bringing that energy here to share it with you. It seems like an incredible journey for a story, one that must have wanted very much to be told.

July 1991 –Amy Lutzke

This is the story that wanted to be told.

No Room for Imperfection

The sun rises into a clear blue sky and illuminates the room where your mother is already awake. She pushes a lock of hair out of her eyes as she bends to smell the roses your father left with her last night. It is February 8, 1940, the day following your birth, your mother's first official day of motherhood.

She muses about the events of the previous day, pulling out bits and pieces that can clearly be remembered. The sound of crisp nurses and wakening women brings her back to today. She looks up to see your father and the doctor striding up the aisle to her bed. It is a moment before she realizes their faces look grim, not amused, and in that moment a vice grips her throat and takes hold.

The doctor begins speaking as he jerks the flimsy curtain meant to induce privacy around her bed and your father gazes into her eyes as he clutches her hand and holds on for dear life.

"Terribly sorry, irreversible damage, abnormal, best not to see." Then a pat on the cheek and "It's the best thing you can do, they'll take care of him there." The gauze wall is jerked back, then he is gone. Your father is crying silent tears but for some reason your mother cannot.

She thinks now of your room back in their small apartment. It is sparsely furnished for times are hard in 1940 but she managed to save enough to buy cheerful yellow paint and pink and blue bunny decals for your bed. As she imagines the emptiness of this room a hard pain like a shard of glass moves into her heart.

Meanwhile in the nursery you are an indistinguishable bundle in a blue blanket, the last crib in the row. The other babies come and go to their mothers, their families. Eager faces push up against the large window, smiling and cooing for everyone but you.

155

You have been found guilty of an imperfection. Without judge or jury your sentence has been cast. In a little while you will leave this sterile environment of women in white, not to go home to your room with the pink and blue bunnies, but to yet another large room with rows of beds filled with indistinguishable bundles surrounded by scurrying women in white.

It is here you will now spend your days and your nights. Your Mondays, your Fridays, your weekends. Christmas, 4th of July and, of course, your birthday. One day seems very much like the next, only the faces in white change from time to time. Faces in white with black name tags on their breasts, except you cannot read and none of the name tags say mom.

There are three square meals a day on square trays with square compartments. The day you reach for the spoon that an aide feeds you with, she scolds and says no. It is so much faster for her to feed you herself and there are so many others waiting to be fed.

Time crawls by in your crib. Sometimes you get to sit on the floor, but exploring is forbidden. They just can't be expected to keep an eye on you wherever you go.

The years will pass by you unmarked by the typical milestones of childhood. Other children will have first words and first steps; photos of them naked on a bear skin rug. Kindergarten, first grade, See Spot run. Training wheels, scraped knees, the wonder of watching a tadpole turn into a frog.

Your sentence, however, prevents you from experiencing these things. Instead of a life, you will receive skilled care. No public education, no friends, no first date, no driver's license, no home and no job. These things are only for the perfect ones of your society, the ones who fit and don't stand out.

The constitution of the country into which you were born states that in its eyes all men are created equal. Unless, of course, they were created imperfectly.

March 1989 –Amy Lutzke

Options' mission, and the soul of its staff's work, is to liberate people and their communities from the many tyrannies that arise when disability is defined as imperfection and becomes a sentence that prevents the pleasures and challenges of ordinary life. This mission animates staff who assist people to find and keep their rightful place in community life by doing tedious, messy, and mundane things that really make a difference.

Index

Authors

Alice Sosinsky 27, 57, 88, 108, 119, 154
Amy Lutzke 17, 21, 52, 54, 66, 101, 117, 131, 137, 143, 155, 156
Carol Lofgren 123, 136, 146
Cindy Herschleb 47
Diane Steele 34, 53, 80, 83, 120, 144, 150
Ellen Backus 15, 75, 107, 145
Gail Jacob 5, 8, 9, 22, 24, 112, 115, 127, 128, 134, 149
Gwen Schmidt 13
Janet Morgan 23, 39, 45, 64, 72
Julie Nichols-Younes 16, 49, 105, 112, 113, 140, 146, 152
Kathryn Mazack 19, 38, 62, 118
Kathy Hart 73
Kathy Lemke 20, 48, 77, 79, 110, 122, 129, 130, 142, 154
Kathy Shenker 153
Kim Turner 29, 30, 37, 46, 55, 56, 63, 74, 80, 91, 92, 94, 98, 102, 114, 142, 150
Leslie Wilmot 14, 23, 28, 56, 136
Maureen Quinlan 18, 69, 74, 81, 95, 106, 132
Missy Fizzell 12, 24, 35, 58, 61, 96, 105
Peter Bazur-Leidy 13, 32, 33, 40, 41, 71, 87, 94, 135, 147, 152
Polly Molenaar 134, 144
Sarah Salzwedel 19, 51, 97, 124
Sid Nichols 30, 40, 43, 50, 67, 68, 85, 90, 93, 100, 104, 125
Theresa Fishler 25, 59, 99, 139
Timothy Boylan 147, 151

People

Al 15
Alan 64
Alex 37, 46, 101
Alice 19, 50, 96, 109, 110, 120, 122, 123, 124, 128, 141
Alyssa 100
Andy 39, 45, 135
Barb 19, 91, 141, 146
Bert, 145
Beulah 14
Bev 32, 135
Bruce 104
Bud 92
Butch 105
Carol 20, 21, 96, 111, 112, 115, 139, 140, 145
Carolyn, 53, 79
Cathy 78
Charlie 37
Cherie, 146

Chris/ Christine 4, 31, 40, 71, 127, 131, 135, 137
Christa 104
Dale 92, 145
Dan 42, 83, 95, 103
Darwin 24, 34, 57, 71, 104, 108, 133, 137, 140, 149
David 12, 51, 58, 141
Dennis 50, 53
DJ 23
Don 51, 135, 145
Donna 11, 23, 24
Dorothy 62, 68
Doug 17, 50
Eileen 16, 98, 119
Eric 34
Frannie 30
Gary 93
Glen 24, 71
Helen 21
Hollis 19, 145
James 107, 145
Jane 129
Jean 6, 15, 39, 66, 71, 75, 135, 145
Jeff 53, 79
Jenell 145
Jim 8, 19, 29, 67, 72
Joe 75, 78,
John 64, 90
Judy 131
Julie 80
Kathy 19, 131, 145
Ken 16, 49, 103, 104, 133
Kerry 92
Kieth 97
Larry 92
Lorraine 27
Mark 94
Mary 61
Mike 62, 113, 135
Nancy 20, 46, 68, 73, 115
Olga 48
P.C. 21, 55
Pat 57
Peter 85, 89
Randi 84, 99
Ray 94
Rita 20, 137
Roberta 56

Rod 101
Roger 149
Ron 40
Sally 30
Sandy 16, 23, 72, 90, 113
Sherry 51
Steve 21
Sue 25, 138
Susan 73
Ted 74
Terry 54, 137
Tom 8, 47, 68, 95, 141
Vivian 27
Wanda 13, 18, 26, 113, 117, 118
Wayne, 80

BEST COPY AVAILABLE